

**Development of a 'communication disability model'  
and its application to service delivery  
in less developed countries.**

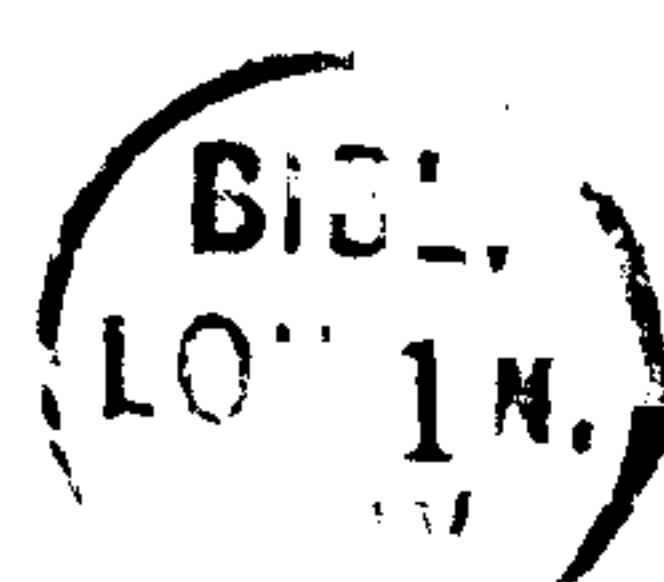
by

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# **DEVELOPMENT OF A 'COMMUNICATION DISABILITY MODEL' AND ITS APPLICATION TO SERVICE DELIVERY IN LESS DEVELOPED COUNTRIES.**

**S.D.Hartley.**

## **ABSTRACT.**

This study began as an investigation into models of service delivery for people with communication disorders in less developed countries. To compensate for the limited data on this client group, exploration of national and international literature, together with perspectives on disability in general, were supplemented by a situation analysis of the services offered to this group of people in Oyo State, Nigeria. These revealed impairment-led activities with low coverage levels and terminology so diverse and inconsistent, that meaningful comparison among limited data available were difficult to achieve.

Three groups of theoretical questions relating to people with communication disorders were developed from the review and analysis. The questions concerned disability, needs and attitudes. The explorations of these form the basis of this research.

Complementary use of qualitative and quantitative methodologies enabled collection of data relevant to the questions posed, through surveys, interviews and focus group discussions, with professionals, parents and community members. Each phase of the data collection was modified to take account of the findings of the previous phase and a process of triangulation was used to validate the data.

The data establishes 'people with communication disorders' as part of the population of disabled people and develops a 'communication disability model' as a means of understanding and developing appropriate service delivery structures. This includes adoption of the term 'people with communication disabilities' as one that expresses and encompasses the author's perception of the target population.

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## AIMS AND PURPOSE

The ability to communicate according to one's own personal need is the very essence of human life. The complexity and power of this skill sets humans apart from other forms of life on this planet and when this ability is impaired, a process of dehumanization results. This strikes at the very heart of a person's identity and the meaning of his existence. Nevertheless, the development of services for people with impaired communication has not been seen as a priority and nowhere is this more true than in less developed countries.

The purpose of this study is to investigate and document the reasons for the low priority given to such services and to identify ways in which the situation could be changed effectively, so that the realities of communication disability can be understood more clearly, and so that professionals can identify their role in developing more meaningful and realistic services to help those who are affected.

The study aims to review the relevant literature, identify key theoretical questions, develop appropriate methodology to address those questions and collect and analyze the subsequent data. The analysis of the data aims to provide information and perspectives that will have an impact on service delivery for people with communication disabilities in less developed countries.



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## **ABBREVIATIONS USED IN THE TEXT.**

<b>AAC</b>	Augmentative and Alternative Communication
<b>AMREF</b>	African Medical and Research Foundation
<b>AIRO</b>	Associazione Italiana Amici di Raoul Follereau
<b>CIIR</b>	Catholic Institute for International Relations
<b>DABB</b>	Disability, attitudes, beliefs and behaviours
<b>DPI</b>	Disabled People's Organization
<b>ENT</b>	Ear Nose and Throat
<b>HMSO</b>	Her Majesty's Stationery Office
<b>IEEIR</b>	International Exchange of Experts and Information in Rehabilitation
<b>NERDC</b>	National Educational Research and Development Council
<b>NGO</b>	Non Governmental Organization
<b>OPCS</b>	Office of Population Census and Surveys.
<b>PHC</b>	Primary Health Care
<b>SCF</b>	Save the Children Fund
<b>SIDA</b>	Swedish International Development Agency.
<b>TALC</b>	Teaching Aids at Low Cost.
<b>UCH</b>	University College Hospital
<b>UNDP</b>	United Nations Development Programme
<b>UNISE</b>	Uganda National Institute for Special Education
<b>WHO</b>	World Health Organization
<b>CVA</b>	Cerebro-vascular accident
<b>UNICEF</b>	United Nations Children's Fund
<b>ILO</b>	International Labour Organization
<b>NCE</b>	Nigerian Certificate of Education
<b>UPE</b>	Universal Primary Education (Nigeria)
<b>GCE</b>	General Certificate of Education
<b>ICIDH</b>	International Classification of Impairment Disability and Handicap
<b>CAMHADD</b>	Commonwealth Association for Mentally Handicapped and Developmental Disorders
<b>IYDP</b>	International Year of Disabled People.
<b>GNP</b>	Gross National Product
<b>JAMB</b>	Joint Academic Matriculation Board.
<b>Medline</b>	Indexes Medical Literature
<b>Popline</b>	Popular Information
<b>Bids</b>	Bath Information and data services
<b>CDS/ISIS</b>	Information system on disability.
<b>Psych lit</b>	Indexes of Psychological Literature

## TERMINOLOGY AND DEFINITIONS.

*“Until something is classified it cannot be quantified”*

*Pope and May.*

This section reviews the definitions and terminology relating to the subject of this study in some detail. It examines and discusses the difficulties which arise from the diversity, inconsistency and insensitivity of the terminology used, and undertakes to identify key terminology and clarify the meaning intended by their use.

It is evident from the literature that the inconsistency and variety of terminology used in the field of speech and language pathology and therapy noted by Enderby and Philipp (1986) and in disability generally (WHO 1980), leads to misunderstanding and misinterpretation of information and data. The literature shows that people with ‘communication disorders’ are not usually identified as a distinct group, but more often divided up and categorized according to impairment, e.g. deaf/hearing impaired, cerebral palsy etc. This is reflected in the structure of services recommended by The Royal College of Speech and Language Therapists in Communicating Quality (van der Gaag 1996) and explained by Oliver (1990) who notes that as the medical profession expanded its activity into rehabilitation they developed services with a medical model perception.

As a result of these predominantly medical perceptions, publications targeting the needs of people with ‘communication disorders’ appear in a wide variety of sources, reflecting the numerous etiologies associated with them. This makes the collection of data on this subject difficult to accumulate, and virtually impossible to compare. Terminology and definitions vary between writers and disciplines, with terms such as speech impairment, speech impediment, speech defect, delayed speech and language development, specific speech and language disorder, communication disorders / difficulties, all being used with a variety of meanings and often without clear definition.



Even the name of the professional who deals with these disorders varies internationally, from Speech Pathologist to Speech and Language Therapist to Logoped to Phoniatrician, with insufficient conformity or agreement of training, content and standards, to allow for agreement, or the right to reciprocate and practice in other countries. This lack of conformity compounds the problem, creating confusion over diagnosis, intervention, professional status, data collection and interpretation.

Finkelstein (1989) emphasizes the importance of sensitive definitions in relation to service delivery and observes that:

‘When services are planned and developed on the basis of concepts and definitions which are not fully appropriate, these problems will remain... it is important to take a clearer and deeper look at basic definitions of disability and appropriate forms of help.....’

“ ...Criticisms of existing services suggest that problems faced by disabled people have been wrongly defined and therefore the type of help provided has not been appropriate” pp 177

Finkelstein (1989) also emphasizes the importance and wisdom of planning services together **with** disabled people and that in order to do so professionals and disabled people must come to speak **the same language**. He says that:

“The interpretation and consequent definition of the real problems disabled people face, critically influence the decisions concerning the kind of help required. pp178

On the grounds that terminology has a major influence on the way in which programmes are perceived and implemented the researcher decided to investigate and clarify some of the definition issues before commencing this study. Careful selection of appropriate terminology should lead to a better grasp of the problems and issues which need to be faced, for developing appropriate models of service delivery for use in less developed countries.

The researcher felt there was a need to identify terminology which:

- was appropriate and relevant to this group of disabled people.
- could provide practical tools for extracting relevant information from the literature.
- could be easily understood by a variety of professionals and development workers.



At the same time as seeking to define and clarify terms, it is understood and appreciated, that this is only the first step towards the appropriate development of services. Myers (1992) argues that the search for clarity requires more than just the specification of terms. He says that :

“Scientific thinking is running well ahead of its translation into programme action based on that thinking” pp. 156.

There is a pressing need for the issues to be explored from many perspectives and for these perspectives to be compared and evaluated so that realistic frameworks guiding the analysis of child survival and development can be identified. Myers (1992) feels that there is a need to identify trends and examine frameworks with policy and programme implications in mind. He laments the divisions which exist in academic thought and service provision that result in the child being

“cut into small pieces” “ in a series of unconnected narrowly conceived analysis” pp.49

It is with these thoughts and sentiments in mind that this researcher seeks to perceive issues from different perspectives and redefine the terminology accordingly, so that a different framework can be developed with service implementation in mind.

## **IMPAIRMENT, DISABILITY AND HANDICAP.**

The distinction between the meanings and the different uses of these three terms is often confused and inconsistent in the literature. Professionals, governments and non-government organizations use them in reports and policies with a variety of meanings which are often ill defined, for example, compare Baldwin, Asindua and Stanfield (1990) who use the WHO (1980) definitions, with Adebayo (1988) who uses ‘the handicapped’ to cover all eventualities, with Central Statistics Office Swaziland (1984) who fail to identify what they mean by ‘disability’, with Coleridge (1993) who argues that impairment and disability carry the two essential concepts, that of loss of function and being disabled by social attitudes. Sometimes the same term may have several different meanings, even within the same document, for example the report by The Federal Ministry of Education Nigeria (1986).



The World Health Organization (WHO) (1980) made an attempt to clarify some of the confusion that has arisen from this lack of consistency with their classification of the long-term non-fatal consequences of disease. They developed the following definitions in the context of the health experience:

**“Impairment:** is any loss or abnormality of psychological, physiological, or anatomical structure or function. pp.27

**Disability:** is any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being (resulting from an impairment) pp 28.

**Handicap:** is a disadvantage for an individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.” pp 29.

Criticisms of the WHO definitions, reviewed in Disability and Rehabilitation 1995, Vol. 17 Nos. 3/4, are based on the unacceptability of their medical orientation, with too much emphasis on the deficiency of the individual, and a lack of attention to the major disadvantages of disability in terms of physical, social and cultural limitations. Oliver’s (1990) reservations, however, stem from the lack of operational need for a distinction between disability and handicap. Whilst he agrees that medical definitions are useful when establishing the cause of an abnormality and sometimes enable a ‘diagnosis’ to be made which might lead to a cure, such diagnoses rarely impact upon everyday living. The conceptual and practical limitations of the WHO definitions are recognised, and consequently are presently under review, but, in spite of their limitations and difficulties, Badley (1993) draws attention to the important impact they have had on the thinking, relating to people with disabilities. The definitions are used and accepted by governments and health professionals in many countries and have certainly helped to add uniformity and understanding internationally. This increased uniformity has been helpful for data collection, statistics and epidemiological studies focusing attention on the ability to perform activities and increasing the awareness of the vast range of disabilities both visible and invisible. They have also provided a very essential base from which modification and suggestions can be made.



Most suggestions for modifications have come from disabled people themselves, as the way they choose to define themselves is often in marked contrast to the WHO biomedical concept of disability. They feel there is a need for more focus on the relationship between themselves and the environment.

During the United Nations decade for disabled people 1980-1990, Disabled People International (DPI) was formed and in 1985 they changed the definition in their constitution to stress that a handicap is a relationship between an individual and his/her environment. The following definition states clearly that DPI feels that society causes disability: (Milton Keynes World Development Education Centre MKWDEC. 1992).

“Impairment”: lacking part or all of a limb, or having a defective limb, organism or mechanism of the body. “Disability”: the disadvantage of restriction of activity caused by contemporary social organization which takes no or little account of people who have impairments and thus excludes them from the mainstream of social activities. pp.27

These and other definitions have implications on models of care and service delivery but the DPI definition shows an increased acknowledgment of the role societies play in disabling people and the need to tackle the environment and educate the community. Finkelstein (1989) says that this requires recognition, time, skill and different information systems and concludes that :

“The key principle in redefining the impact of disability is to redefine disability as a dynamic relationship between:  
-people who have specific physical and mental impairments and  
-the social and physical barriers imposed by a world designed for able bodied living.” pp 179.

A qualitative study by Hallberg, and Carlsson, .(1993) challenged the WHO terminology particularly for disability and handicap. The study aimed to generate theories of definition from collecting data rather than expounding and verifying existing theories. Hallberg and Carlsson (1993) claimed to reach similar conclusions to that of the Canadian revision of the WHO definition (Frougeyrollas et al, 1989) and

“a Swedish version of an environmentally-related definition” pp 82 “handicap is seen as the outcome of the interaction between the individual with the disability and the environment, corresponding to specific life habits and social roles in a particular society” pp 83

The existence and results of such studies support the importance and role of interaction in the process of disablement. They conclude by suggesting that a description of the interactive process in which a handicap is created, might be seen as a supplement to a classification system.



A similar perspective, recognising the impact of the social environment in the creation of disability, is reported by special educationalists and is reflected in the Salamanca report of the World Conference on Special Needs Education (UNESCO 1994) Building on 'Education for All' initiatives, the report recognises that the origins of children's difficulties

"lie not just with themselves but also in the social environments in which they are living" pp15

The report attempts to develop a framework for tackling the practical implications of this different perspective.

From a Social Service perspective the need to identify the prevalence of disability as a basis for the development of services lead the Office of Population and Censuses (OPCS) to investigate the concepts of appropriate definitions (Bone and Meltzer 1986). The scales developed for use in this survey essentially follow the WHO (1980) classifications of impairment, disability and handicap but do reflect an understanding of the importance of the social factors involved in creating a disability and also include 'Communication disability' as an identifiable category. In practical terms, as Kersner et al (1995) point out in their Zimbabwean study, people may make little distinction between these terms and questionnaires and interaction with local people should reflect a sensitivity to this fact. This is summarized by Miles, S. (1990) who points out that:

Disabilities can only be defined by their context pp 4

The researcher has endeavoured to bear this in mind while conducting this study.

Although disability is a feature of life in both developed and less developed countries and can affect anybody at any time, Coleridge (1993) points out that

"There is a close relationship between poverty and disability: malnutrition, mothers weakened by frequent childbirth, inadequate immunization programmes, accidents in overcrowded homes, all contribute to an incidence of disability among poor people that is higher than people living in easier circumstances."

It also:

"increases isolation and economic strain, not just for the individual but for the family." pp 64



At the same time technical development does not necessarily mean less impairment. More health care often results in people living longer or surviving illnesses which would previously have been fatal thus increasing the incidence and prevalence of impairments. Werner (1989) also observes that major long term health improvements are not necessarily determined by specific health interventions but are often more affected by general issues related to the development of a better standard of living, such as the general economy or political situation. It would seem therefore that disability is an important development issue in both developed and less developed countries.

In conclusion it would seem that the following concepts are supported by the literature and fit well with the experience and observations of the author in 20 years of setting up services for people with 'speech and hearing disorders' in less developed countries:

- disability is a social rather than an individual issue.
- disability is not a single issue with a single simple or technological solution
- disability is a development issue.

## **MODELS OR APPROACHES TO DISABILITY.**

According to Coleridge (1993) a 'model' is something which makes sense or organizes information into a useful and retrievable pattern or structure. Defining a model helps us to understand how something works, and enables us to break a process into its component parts. Once these parts are identified they can be compared with other models.

### **The traditional model.**

Coleridge (1993) describes the traditional model as a pattern of behaviour which has developed in a given area over a period of time and is recognized by a significant number of people. Its structures are usually part of religious or cultural beliefs. On this basis disability is often seen as a punishment for bad deeds or the result of spiritual anger, disabled people are unfortunate, unclean or blemished.

### **The individual model.**

The Individual model of service delivery for people with disabilities is a model which concentrates on the individual as the focus for all its activity. Milton Keynes World

Development Education Centre (MKWDEC) (1992), identifies two types of individual models, the medical and the charity model:

**The medical model** is taught to doctors in medical schools. The disease is seen as paramount and it is assumed that the similarities between people with the same disease are greater than the differences. According to MKWDEC (1992), it considers the disabled person as ‘the problem’ and uses terminology such as ‘sick’ ‘invalid’ ‘defective’ ‘needing a cure’ and ‘normality’. It views disorders and impairment as ‘abnormalities’ which need to be ‘cured’ and ‘corrected’. The emphasis is on changing the individual to be more acceptable to society and the ‘patient’ is seen as dependent on the medical personnel.

**The charity model** is also an individual model associated with passivity and gratefully receiving help. According to Stubbs (1993), it originates from traditional and religious origins and has its base on the interaction between dependency, helplessness and superiority. Carey (1995) says that:

“Charity has too often robbed us of our dignity and independence” pp 12.

MKWDEC (1992) say that:

“the charity providers, like medical experts, often decide what they think disabled people need” pp 3.

and the money donated affects the image of the people concerned. They note that charity initiatives often find piecemeal solutions.

MKWDEC (1992) conclude that the individual model is inadequate as it highlights only some of the things which disable a person in society and ignores the major barriers that people face. It points out that disabled people themselves feel that they are disabled more by the way society is organized than by their medical condition, which, they feel, is only a small part of their problem. They suggest that impairment may account for as little as 10% of the disability.

**Three additional individual models:**

**The functional model**, an individual model particularly relevant to therapeutic intervention as it is based on assessment and improving abilities to carry out activities associated with daily living. The functional status of a disabled child refers to the extent



to which a child with an impairment can perform a range of activities within their environment. Although Memel, (1996) describes it as a model that takes the emphasis away from the disease, it still encourages dependency, and the patient's view is rarely sought.

**The educational model** according to Stubbs (1993), is based on the individual model, with the problem identified as 'the children', the number of 'handicapped' children in the class, what they 'suffer' from and what they can do to improve their performance.

In **The expert model**, professionals are regarded as having a specialized body of knowledge and skills with which they can objectively assess and meet the needs of service users. The perspectives of users are largely rejected as uninformed and irrelevant. The role of the user is to be a passive recipient of services and to comply with advice or treatment provided by the professional. This approach is most commonly associated with institution-based service provision (Coleridge 1993).

## **SOCIAL MODEL**

In the social model, the medical condition is seen to be only part of the problem with environmental, attitudinal and institutional barriers contributing to the disability. According to Memel (1996) the role of society is seen as paramount and disability as the disadvantage or restriction of activity caused by social organization which takes little notice of the needs of people with impairments and thus excludes them from integration and participation in society.

DPI (1986) Stresses that a handicap or disability is a

"relationship between an individual and his/her environment" DPI (1986) pp 2 and shows an increased acknowledgment of the role societies play in disabling a person.

Coleridge (1993) describes a social model of disability as one that

"starts from the point that integration is ultimately about removing barriers." pp 73 The advantages of the social model are that it addresses the consequences of disability and takes into consideration the views of the disabled people themselves and the people who care for them.



## **SEARCH FOR TERMINOLOGY TO DESCRIBE THE TARGET GROUP.**

The problems arising from inconsistent terminology describing the target group have already been discussed. In the search for new terminology, several terms were rejected: All terms which included “**speech**” as part of the terminology were rejected, for example, “speech impaired” or “speech disordered”. Speech is a highly specific term, with no inference in its meaning to cover language, interaction or communication and was therefore considered inadequate for the task in hand.

All terms which included “**impaired**” for example, “communicatively impaired” were also rejected. The term places the blame on the individual, it disregards the social implications and looks to the ‘client’ for change. It excludes people disabled by society and people with “hidden” impairments. Additionally, as with ‘disorder’, the impairment may or may not cause a disability.

### **Recognition of the importance of ‘communication’ as a key factor.**

It was decided to use the term ‘Communication’ for this research, as one which encompassed a wider range of functioning in its meaning, and which was more appropriate than ‘speech’ or ‘language.’

Communication refers to a process of interaction and sharing between living creatures and although spoken communication is a widely used form of communicating, there are other modes such as reading, writing, body language, seeing and signing. Some of these alternative modes of communication are unavailable to certain groups of people. For example a vast number of illiterate people are excluded from written forms of communication and even larger numbers of people are excluded from communication with people who are deaf, if they are unable to use sign language. These alternative modes of communication, however, form the corner stone of therapeutic intervention for people whose speech is too poor to be understood.

This is possibly why the importance of the ability to communicate (rather than to speak) as a target for therapy and service provision, is a concept which has become stronger in the speech and language therapy profession in recent years, with many departments and much literature in the UK and USA choosing to reflect its importance by using the word



more frequently, e.g. Department of Communication Disabilities, Department of Human Communication, Department of Communication Sciences and “The European Journal of Disorders of Communication”.

This represents a move away from words such as ‘speech’ and ‘language’ “logopedics” ‘phoniatics’ which over the years have often been found to be inadequate and misleading.

### **‘PEOPLE WITH COMMUNICATION DISORDERS’.**

The term, ‘people with communication disorders’ is used in the first part of this research and is defined to include **all** people with communication disorders regardless of the cause of the impairment. It therefore includes people with hearing impairments. Although the researcher was unhappy with the term ‘disorder’, as this gave a ‘medical’ focus, with emphasis on ‘abnormality’ and ‘cure’, an appropriate alternative was elusive.

‘People with’ was used to emphasize the importance of considering the people under study, whether children or adults, as **people first and foremost**, people with needs, wants, feelings, personalities and tempers. It was felt important to communicate this fact in the title that referred to them, and not to exclude it by referring to ‘the deaf’ or ‘the mentally handicapped’.

### **‘PEOPLE WITH COMMUNICATION DISABILITIES.’**

The term ‘people with communication disabilities’ evolved during the process of this study, as one which describes the desired target group more clearly than any of the other alternatives. This was not, however, identified until the third and final stage of the research. The literature review, situation analysis and the first two stages of data collection use the terminology ‘people with communication disorders’ as defined above.

As already described, the definitions of ‘Disability’ by WHO (1980) and DPI (1992) can be seen to have a different emphasis. The WHO definition identifies disabled people themselves as being the “problem” and refers to “normality”, whereas DPI gives great importance to the environment and society’s role in creating disability. As a result of



the DPI definition, an increasing recognition of the role that societies' play in disabling a person has developed, and the WHO definitions are under review. It is a combination of these definitions with more emphasis on the process of interaction that the researcher envisages will present a complete picture.

It is appreciated that the term 'people with communication **disorders**' would include some people without a communication **disability**, for example someone with vocal nodules resulting in a husky voice quality may be considered to have a voice 'disorder' but this need not necessarily result in a communication disability. Such a person would not be a target for this study. However the term 'people with communication disorders' is not satisfactory for the groups of people whose difficulties are not easily attributed to medical etiology, as in the case of a child with a learning disability or phonological 'disorder'

**'Communication disability'** may not be a commonly used term but is not new. It has also been used by the WHO in their International Classification of impairments disabilities and handicaps (1980), in which they define communication disabilities as;

'an individual's inability to generate and emit messages and to receive and understand messages.' p154

WHO (1981a) say this may result from an impairment of cognitive, motor or sensory ability, or a specific impairment of language functioning, and include messages transmitted through the sensory channel of vision as well as hearing, talking, understanding, listening, reading, writing, lip-reading, signing and gesturing. These definitions do not accommodate the social and interactive aspects of communication disability which the researcher is keen for the term to reflect.

The use of this term does relieve the need to have a separate category for hearing impaired people, as hearing impairment is just one of the causes of a possible communication disability and under this definition does not need to be in a separate category.

In summary the term 'people with communication disability' develops in this study to cover aspects of human endeavour which fail to meet the needs of an individual's desire to communicate his wants, fears and feelings in the giving and receiving of information to other human beings.



It is noted that much of the literature used in this study chooses alternative terminology to describe the group of people which interest them, for example:

'speech and language disorders'(Marshall 1992 pp6)  
 'communication problems' (Carbello de Neri 1992pp2)  
 'communication impaired people' (Coleridge 1993 pp60).

As it was not possible to make clear differential definitions of each of these terms, nor was it possible to ignore them, it was decided that in the process of quoting and discussing such data, the terminology of the author would be used in inverted commas.

## **MORE DEVELOPED AND LESS DEVELOPED COUNTRIES.**

Almeida-Klein(1995) argues that

"The concept of development as a more or less linear series of changes, proceeding from primitive to other more sophisticated methods of production and from everyday hardship to a more comfortable life by means of technical improvements, is a relatively recent notion. No such idea existed in the middle ages" pp13.

As such it is a very western concept and linked to the modern industrialized process since it is through this process that standards of living have been raised. Consequently Almeida-Klein (1995) argues that in most 'Third World' countries the whole notion of development is still alien to cultural traditions and the definition of 'development' is an artificial demarcation.

Consequently related terminology is an artificial attempt to impose a division of the countries of the world into 'developed' and 'developing' and none of the terms used to refer to countries which are, in the main, not industrialized and which are targets of 'Western' Aid and development are particularly satisfactory, 'the third world' 'the south', 'developing countries' 'less developed countries' are all unsatisfactory terms with unfortunate connotations. Similarly 'the west' 'developed countries' 'the north' 'industrialized countries' are equally misleading and unsatisfactory. These issues are explored with more vision in a statement made by the International Body of the Bahai Faith (1994) who observe that the assumptions directing most of present day development planning, are defined in terms of the successful cultivation of material prosperity and that this material prosperity is associated with certain regions of the world. They do not



however make any suggestions for more appropriate terminology and the terms already mentioned are widely used by Governments, aid agencies, including United Nations Agencies. It seems difficult to find practical alternatives.

The researcher decided to use the terms 'more developed and less developed countries' which reflected the continuum of development illustrated by the Population Crisis Committee (1992) in the Human Suffering Index. Nevertheless, the terms are used reluctantly, and in the knowledge that, for some people, they still have derogatory connotations. When quoting information in the literature review, however, the terminology of the author is used in inverted commas.

### **ANGLO-PHONE AFRICA.**

This term refers to the countries on the African Continent that use English as an official language. 17 of the 55 African countries use English as a medium of education and communication, (Instituto del Tercer Mundo 1994) There are seven others that use English in a more limited capacity. It is only the countries in the former group that are referred to as Anglo-phone Africa. They are: Botswana, Gambia, Ghana, Kenya, Lesotho, Liberia, Malawi, Mauritius, Namibia, Nigeria, Seychelles, Sierra Leone, South Africa, Swaziland, Uganda, Zambia and Zimbabwe.

### **COMMUNITY BASED REHABILITATION (CBR)**

The idea that a 'grassroots' and community based type of service would benefit larger numbers, together with the anti-institutional bias, and the principles of primary health care, gave birth to CBR as a new approach. CBR is part of a movement which received global recognition of the World Programme of Action for Disabled Persons and the basic guiding document for the UN Decade of disabled persons, United Nations.(1983), says that:

"The underlying philosophy of this movement was that integration of disabled persons into society had priority over the creation of a special environment and special services for disabled people. The call was heeded in the developed world with closures of institutions and movement towards 'mainstreaming' and 'normalization'". pp 12



To find a cost effective substitute for rehabilitation in institutions was also the idea guiding policy recommendations for less developed countries (LDCs). Centrally based rehabilitation institutions had, in terms of quality and numbers served, led to great disillusionment their services only reached a few. CBR was developed and promoted by the WHO in the early 1980's, as the most effective and affordable means of providing rehabilitation for all in LDCs. The WHO manual 'Training in the Community for people with disabilities' (Helander et al 1989) provided a prescriptive training for community members in basic rehabilitation techniques. It was recommended to governments of less developed countries and implemented by a host of international and governmental organizations in a variety of very different cultures and social and economic circumstances.

Since the inception of CBR a recognition of social causes and dimensions of disability has led to a change in emphasis in disability programmes and in 1994, three UN agencies issued a joint statement on CBR in the document 'CBR with and for people with disabilities.' The definition by the ILO, UNESCO and the WHO (1994) says,

"Community based rehabilitation is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities.

CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services." pp 4

The process of CBR has attracted unqualified support from all corners of the globe and according to Miles (1993a), the terminology is now used in at least 80 countries. However the unanimity of those using it as an approach to the disability problem, conceals the fact that there is great disparity in its interpretations and this has generated controversy over its application in practice. The terminology is used to refer to a wide range of activities. Further discussion of CBR can be found in section 1.4.5.

## CHAPTER 1. LITERATURE REVIEW.

*“Even a journey of a thousand miles begins with a single step.”*

*Ancient Chinese Proverb*

### 1.1.0. INTRODUCTION AND OVERVIEW.

Chapter 1 of this thesis reviews the literature concerning people with communication disorders<sup>(1)</sup> who live in less developed countries high on the Human Suffering Index as defined by the Population Crisis Committee (1992). The key terms used in this research are defined in the previous section under definitions and terminology. Chapter 1 is divided into two sections:

- \* incidence and prevalence
- \* service delivery options in less developed countries.

Initially, the intention was to review literature about Nigeria only, as this was the geographical location in which the researcher had extensive work experience. It was intended that this information would then be compared with information from other Anglo-phone African countries. However, initial searches concerning the incidence and prevalence of people with communication disorders, and the services offered to them in Nigeria, yielded such a small amount of information, that it was considered expedient to tackle the issue in two different ways:

- \* To look for, and include, relevant data from other countries high on the Human suffering Index (Population Crisis Committee 1992) with an emphasis on information from Anglo-phone African countries.
- \* To initiate a situation analysis of services for people with communication disorders in Oyo State, Nigeria. Full details can be found in Chapter 2 .

The paucity of information about people with communication disorders in less developed countries may be explained in a number of ways :

1. The term 'communication disorders' is used in the initial sections of this research as the majority of the literature explored uses terminology more closely related to 'disorders' than 'disability'. The decision to adopt 'communication disability' as the desired terminology is made during the process of data collection.



- \* where survival is threatened, the ability to communicate, or lack of it, may not be of paramount concern to individual's families communities and governments.
- \* there is a general tendency to only pay attention to what can easily be observed.

As Stone (1995) points out

"It is a truism that 'the squeaky wheel gets the grease' ...Why do we tend to focus on visible disabilities and ignore the presence of invisible disability? This denial has oppressive consequences' p 413.

- \* by appreciating and understanding that there is a lack of information and attention given to people who cannot speak for themselves.
- \* the tendency to presume that the inability to speak means the person has nothing worth saying or communicating and is therefore of no interest or concern.
- \* the assumption that because speech and communication usually develop naturally as part of general development that "anyone / everyone can talk" and those who cannot must be 'stupid'.
- \* people involved in collecting data or creating literature in this area have been largely medically orientated. They operated from a view point based firmly in impairment-related categories. As a result, 'communication disorders' are rarely viewed as an entity because they are associated and secondary, to a number of different impairments groups.

### 1.1.1. THE AIM OF THE LITERATURE SEARCH.

The motivation to commence this research programme arose from the researcher's own work experience over a period of 25 years. This experience involved setting up and providing, mainly clinical services and undergraduate training programmes, in East, West and Southern Africa. The services and training were directed towards improving knowledge and skills,

for and about, people with communication disorders. Over the years it became obvious to the researcher, that using a medical/individual model as a basis for service delivery and therefore subsequent training, did not facilitate the provision of appropriate services for those in need. The motivation for this research was to explore alternative service delivery structures and move towards health service provision as a sustainable state as described by King (1980).

In the absence of previous studies of its kind and in order develop an information base, this literature review sets out to consider relevant documentation related to people with communication disorders who live in less developed countries high on the Human suffering Index (Population Crisis Committee 1992).

### **1.1.2. METHODS USED TO GATHER INFORMATION.**

The methods used to collect information about the issues were:

- \* Personal communications
- \* UN Publications
- \* Formation of the organization 'Communication Therapy International'
- \* Manual searches for information in libraries both in UK and Nigeria
- \* Computerised searches through key words on data bases, namely: Medline, Popline, Bids, CDS/ISIS at ICH and AHRTAG, Libertas, Psych Lit.

As the literature search progressed the author moved from a medical model perception through to a social model approach (these terms are defined in the previous section.) The different perception opened new avenues for exploration, and a wealth of literature in the area of disability studies which seemed relevant to the subject under study.

Additionally in 1993, the study moved from the National Hospital's College of Speech Sciences (NHCSS) to the Centre for International Child Health (CICH) at the Institute of Child Health (ICH). This facilitated the change of emphasis in the literature search and also encouraged the exploration of disability related issues.



Material has continued to be collected over the study period and it can be seen from the review that some of the most relevant information is emerging from very recent publications, publications which were not available at the commencement of this study.

### 1.2.0. INCIDENCE AND PREVALENCE

Published literature about incidence and prevalence data concerning people with communication disorders is very limited and even in relatively developed parts of the world it is only recently that surveys and studies have been made to estimate the size and needs of this population group.

Collection of data is problematic because:

- \* Viewing 'people with communication disorders' as an identifiable group, is a relatively new perception. Most previous, and many present studies, are impairment related i.e. related to hearing impairment or cleft palate. Information from these studies is relevant, but incomplete, particularly when related to service delivery, and therefore often misleading.
- \* People with communication disorders are not a homogeneous group. Their disorder and resulting disability can be from a wide variety of causes (Enderby and Philipp 1986).
- \* Communication disorders themselves are often secondary to a variety of underlying medical problems or developmental disorders (Enderby and Philipp 1989).
- \* There is no 'absolute' relationship between the underlying medical problem and the communication disorder. Only a proportion of each of these medical and developmental categories will have a resulting communication disorder (Enderby and Philipp 1986).

- \* The proportion of people with a communication disorders identified within different medical and developmental categories is variable and the published literature gives conflicting prevalence data(Quirk 1972, Enderby and Davis 1989, Enderby and Philipp 1986).
- \* Communication disorders have several dimensions. They may be:
  - congenital or acquired,
  - permanent or transient,
  - mild, moderate or severe, distributed on a continuum
  - affecting all, a few or only one mode of communication eg. expressive / receptive, oral or manual.

Different results will be obtained depending on the specific area of functioning being assessed and the identified 'cut off' point.
- \* Even between the professional groups concerned, definitions of many of the resulting handicaps are not uniform. Terminology is used with different implications of meaning. e.g. Is there a difference between developmental dysarthria and phonological disorder or acquired dyspraxia and developmental verbal dyspraxia? Does delayed speech development mean the same to a speech and language therapist as it does to a medical practitioner? Is there international agreement about the exact meaning of 'impairment' 'disability' and 'handicap'?
- \* Different attitudes and cultural perceptions affect how people observe situations. What may be considered by some as 'different', may be observed by others as "the same".
- \* As argued in the section on definitions and terminology, the researcher considered it important to observe the effect of the communication disorder on the person themselves and eventually uses the term Communication



**disability** which includes recognition of the effect of the disorder on the person and their response to it. With this concept in mind it becomes relevant to question whether or not incidence and prevalence surveys can measure disability or if they in fact only measure the incidence of the underlying disorder? This might explain why Thorburn (1991) and Morris (1995) are both cautious about the efficacy of using prevalence rates to measure need, and Anacleiti (1992) emphasises the importance of people being encouraged to identify their own needs, not the ‘experts’, as a basis for development.

- \* Variation of the above factors quite simply result in the collection of different sets of data which are not generally compatible or comparable. Unfortunately this is not always appreciated and comparisons are made which often result in misunderstandings and miscalculations.

The factors mentioned above are further compounded when operating in a less developed country, where there are:

- \* changing sociocultural values,
- \* multilingual and linguistic variations,
- \* a paucity of base line information,
- \* a shortage of resources and personnel,
- \* poor infrastructure,
- \* different expectation levels.

All these factors combine to frustrate efforts to quantify the issues related to this field and contribute to the difficulty in quantifying prevalence rates.

In developed countries, estimates of incidence and prevalence have arisen from many years of service implementation. Unfortunately this method of data collection and source of information is not generally available in less developed countries due to very limited

development of service structures which have also been poorly documented.

In spite of reservations expressed by WHO (1981a) that it was more important to discover a population's rehabilitation needs, than to discover the prevalence of disability itself, it would seem that information of a demographic nature is still considered a prerequisite to formulating appropriate service delivery structures (Miles 1990a), and according to Enderby and Davis (1989) 'the speech and language disabled' would be no exception. Failure to do this could result in inappropriate service delivery patterns developing, which use up the limited and scarce resources and do not meet the needs of the people concerned. Saunders and Miles (1990), however, while recognising that Ministries in less developed countries seek such information, argue that it can be best obtained by using data already collected and by setting up structures to collect data from existing services. They feel that service development should take priority and that surveys

"can be wasteful or even counter productive" pp 1.

They support the work carried out in the primary health care field by Chambers (1994) and Annett and Rifkin (1995) on Rapid Participatory Appraisal, developing practical ideas and guidelines to enable health managers to collect data using existing records, observation, key informants and then together with community participation develop a plan of action which is based on community health needs.

Enderby and Philip (1986) undertook research to estimate and calculate the number of people with 'speech and language handicap' in the UK by examining the relevant data from associated fields, which had been collected over recent years. Their work emphasised that reliable estimates of the size of the 'speech and language handicapped' population are needed for effective service planning in the UK, but also point out that the World Health Organisation (WHO) (1980) emphasises the need for efficient planning in the health care process in **ALL** areas of the world. The importance attached to demographic information of this kind, even in less developed countries, is illustrated by the reluctance of Ministers from these countries to initiate the planning and development of services without the data to support the proposals (Saunders and Miles 1990).



The absence of incidence and prevalence data together with perceptions of low priority, have led to a similar pattern of service development for people with communication disorders in less developed countries to that found in more developed nations. Services have been few and of low priority, often initiated on an ad hoc basis. The emphasis on 'cure' and 'care' described by Finkelstein (1989) and the medical, impairment, hospital based service approach, has been mirrored repeatedly in overseas aid programmes to less developed countries.

As in more developed countries, much of the initial work is carried out by non- governmental organisations (NGO's). These can be either local or internationally based and show evidence of little monitoring, inter-co- operation, recording or evaluation (Magagual 1989). They tend not to be part of any overall national service plan.

Three methods of gathering and estimating incidence and prevalence data concerning people with communication disorders are :

- \* Extrapolate data from incidence and prevalence studies in more developed countries.
- \* Use locally collected data about people with communication disorders.
- \* Consider people with communication disorders as part of the cohort of disabled people and use the relevant locally collected data.

These three methods are explored in the sections which follow.

### **1.2.1. INTERNATIONAL PERSPECTIVE: Extrapolation of data concerning people with communication disorders using incidence and prevalence studies carried out in more developed countries.**

In the absence of locally gathered information, a strategy which is often used, is to take surveys and estimates made in more developed countries and superimpose the results onto populations and population groups from less developed countries. This method is often used to calculate the probable size of a specific population in the other country and has been used by numerous professionals and government bodies. For example, Holborow et al (1982), Federal Ministry of Education, Nigeria (1986), Al-Shihabi (1992), Saunders and Miles (1990) WHO (1981a).

Unfortunately this process cannot, and does not, take into account the local demographic, cultural, linguistic and social variations with their different attitudes and expectation levels. The resulting information is therefore inherently inaccurate, (Hartley and Wirz 1993) and comparisons between surveys somewhat meaningless, (Ross and Vaughan 1984). The wide variety of survey methodologies used, also contribute to the wide variation of final data. This is well illustrated by the startling differences identified in a report by Haggard and Hughes (1991) on screening for hearing impairment.

Table 1. (see page 40) summarises the variation in prevalence data reported by different surveys in UK and USA. For example the health interview survey of parents in the USA National Centre for Health Statistics (1971), reports a 1.2% prevalence rate of children with 'speech handicaps' in comparison with Peckham's (1973) longitudinal study of a national sample of 15,000 seven year old children born in one week of 1958 in the UK, showing a 10-13% prevalence rate. It would seem impossible to estimate what proportion of the difference between these studies is due to different data collection methods, different age groups, different definitions and different criteria for 'speech and language disability' or 'impairments', and what proportion is due to the actual different prevalence rates of communication disorders in the two countries.



It is interesting to see the similarity between estimates of the 1981 ASHA survey of the literature by Leske (1981), and the work of Enderby and Philipp (1986) who both conclude that the overall accepted prevalence rate of 'speech' problems is around 5% (This includes those resulting from hearing impairment). Both these studies use similar methodology.

Enderby and Philipp (1986) felt that there was a need for a revised estimate of the size of the 'speech and language handicapped' population of the UK from the one put forward by the Quirk report 1972. They estimated that 800,000 persons have a 'severe speech handicap' i.e..1.5%, which they define as people who

"have difficulty making themselves understood by anyone other than their immediate family" pp 153

and that 1.5 million people, or 3.5% of the population have a 'moderate speech handicap', where the:

'speech and language is noticeably disordered but not necessarily unintelligible.' pp 162

This makes a total prevalence rate of 5%. The earlier report from the UK by Quirk (1972) reveals a lower percentage, but as Enderby and Davis (1989) point out, the proportion of cases in each study, that would need or benefit from therapeutic intervention, is a different issue which should, according to Wirz (1995) not only depend on the impairment/disorder but also on the disability the impairment creates and the type of therapeutic intervention offered.

In Table 1 these rates are then used as a basis for calculating the possible prevalence rates of people with 'speech and language handicap' in Africa, using the population estimates from the Third World Guide 93/94, Instituto del Tercer Mundo (1994). Taking the prevalence rates of Leske (1981) and Enderby and Philipp (1986) and noting the high proportion of African people living in Nigeria, (approximately one quarter of the population of sub-Saharan Africa, and nearly half Anglo-phone African people live in Nigeria), it can be seen that there would be an estimated 5.45 million people with communication disorders in Nigeria.

**Table 1. Extrapolation of data about people with communication disorders using population estimates from the Third World Guide 1993-94 and Readers' Digest Association Limited (1985) \* and \*\*, together with prevalence rates from surveys carried out in USA and UK.**

	Population estimates based on Third World guide 93/94 except for UK & USA	Enderby and Philipp (1986) 5% (1.5 +3.5%) same as ASHA review (1981)	National Centre for Health Stats (1971) USA. 1.2%for UK & USA	National sample of children Peckham. UK (1973 ) 10-13%	Quirk (1972) UK. 2-3%
All Africa	530.9m	26.5m	6.4m	53m-69m	10.6m-15.9m
Sub-saharan Africa	415m	20.8m	4.98m	41.5m-53.9m	8.3m-12.5m
Anglo-phone Africa	242.3m	12.1m	2.9m	24.2m-31.5m	4.8m-7.2m
Nigeria	109.17m	5.45m	1.31m	10.9m-14.2m	2.2m-3.3m
Uganda	18m	0.9m	0.2m	1.8m-2.3m	0.36m-0.5m
Lesotho	1.8m	0.09m	0.02m	0.18m-0.23m	0.04m-0.05m
U.K.	56.236m *	2.81m	0.8m	5.6-7.3m	1.12m-1.6m
U.S.A.	226.505m**	11.325m	2.7m	22.6-29.4m	4.5m-6.8m

**Note:** The large discrepancy which exists between the various estimates gives a very wide range of possible prevalence rates.

As previously indicated the methods used in these surveys varied:

- \* Enderby and Philip (1986) used literature to identify the medical and other problems associated with speech and language handicap and estimated the incidence and prevalence of speech disability within these groups.
- \* Leske (1981) used a review of the literature and surveys and reached a consensus.
- \* The National Centre for Health Statistics (1971) used a health interview survey.



- \* Peckham (1973) used a longitudinal survey sample of 15,000 children.
- \* Quirk (1972) used the proportion of patients with specific medical problems known to cause speech and language disorders, and selected the median or prevalence rate to estimate the number of speech and or language handicapped persons. Similar to Enderby and Philipp (1986)

Extrapolation of figures can also be used as a basis for creating and examining more detailed breakdown within a client group, and in the absence of such information at a local level it was felt worthwhile to extrapolate data from some of the more detailed work of Enderby and Philipp (1986). Extrapolated figures and percentages were used as a method of calculating the possible size and dimensions of the number of people with communication disorders in Oyo and Osun States in Nigeria, the area of situation analysis, see Chapter 2.

It was decided to amalgamate some of the eighteen categories used by Enderby and Philipp (1986) on the grounds that the differential diagnosis between these categories was largely irrelevant in countries where identification of these groups was immaterial to the choice of intervention available. The details of these amalgamations can be seen in Table 2. The 10 categories created are listed in Table 3a and b.

**Table 2 Categories of underlying medical disorders amalgamated to include the less prevalent groups.**

Head Injury	includes cerebro-vascular accident
Voice	Dysphonia Laryngectomy
Degenerative Disorders	Parkinson's disease Multiple sclerosis Muscular dystrophy Motor Neurone disease Myasthesia <del>gravis</del> Huntington's Chorea Fredricks Ataxia

**Table 3a. Estimated numbers of people with 'severe speech and language disorders' as defined by Enderby and Philipp (1986) in Nigeria, Oyo and Osun State and sub-Saharan Africa. (Information is tabulated according to Enderby and Philipp prevalence rates of different client groups.)**

Disorder	Enderby and Philipp (1986) estimated no. of sev. sp. & lang. handicapped people per 100,000	Calculated no. of people with sev. sp. and lang. handicapped in Nigeria using census data	Calculated no. of sev. sp. & lang. handicap in Oyo/Osun States using 1991 census	Calculated no. of sev. sp. & lang. handi-capped in sub-saharan Africa. Third World Guide data
Mental Handicap	800	708,000	27,904	3,320,000
Stammering	70	61,950	2,442	290,500
Pre-school	130.4	203,904	8,036	956,160
School Age	200	177,000	6,976	830,000
Head injury	130	115,050	4,534	539,500
Deafness	45	39,852	1,570	186,750
Cerebral Palsy	20	17,700	698	83,000
Cleft Palate	19	16,815	663	78,850
Voice disorders	12	10,620	419	49,800
Degenerative disorders	38.3	33,895	1,336	158,942
Total	1464.7	1,384,759	54,578	6,493,505

\* The figures are based on the 1991 population census figures of 88,500,000 for Nigeria, 3,488,789 for Oyo and Osun States and Third World Guide estimates 1994/5 for sub-Saharan Africa giving a total population figure of 415,000,000.



**Table 3b. Extrapolated data using Enderby and Philipp (1986) estimates for people with 'moderate speech and language handicap' in Nigeria, Oyo and Osun States and sub-Saharan Africa. Information is tabulated according to different client groups.**

Disorder	Enderby and Philipp (1986) estimated no. of sev. sp. & lang. handicapped people per 100,000	Calculated no. of people with sev. sp. and lang. handicapped in Nigeria using census data	Calculated no. of sev. sp. & lang. handicap in Oyo/Osun States using 1991 census data	Calculated no. of sev. sp. & lang. handicapped in sub-saharan Africa. Third World Guide data
Mental Handicap	575	508,875	20,056	2,386,250
Stammering	1	885	34	4,150
Pre-school	460.8	407,808	16,073	1,912,320
School Age	200	177,000	6,976	830,000
Head injury	180	159,300	6,278	747,000
Deafness	75	66,375	2,616	311,250
Cerebral Palsy	85	75,225	2,965	352,750
Cleft Palate	38	33,630	1,325	157,700
Voice disorders	19	16,815	663	78,850
Degenerative disorders	77.9	68,942	2,717	323,285
Total	2,710.7	1,514,855	59,712	7,103,555

\* Only figures for the Enderby and Philipp categories considered to be severely or moderately affected were included in table 3 a and b. It was felt inappropriate to include figures relating to people with only a slight speech and language handicap.

It can be seen that extrapolation from data collected in more developed countries is a relatively simple calculation. It is unfortunate that the results are of limited value.

Extrapolating from Enderby and Philipp's (1986) UK estimates is problematic because:

1. The estimates are based on client groups identified by 'disorder' or 'impairment'.  
E.g. hearing impaired, voice disorders. Such client groups are not so easily identifiable in LDCs.
2. Calculations of this kind are based on population census figures which are in themselves questionable. For example the results of the 1991 census from Nigeria have been contested by several States in Nigeria. Inexplicable discrepancies like those highlighted by Nwankwo (1992) support the possibility that the population of Nigeria is nearer 120 million than the official 88.5 million. Because of this dispute, census details remain unpublished. These discrepancies serve to emphasise the shaky ground on which any resulting calculations stand. In countries where the original census data is inaccurate, it is difficult to know what interpretation one can give to extrapolations on a specific population.

**However, the figures do show that:**

- \* It is likely that a significant number of people in Nigeria and other LDCs have a variety of different communication disorders.
- \* The process of extrapolation may not give accurate figures, but it does allow speculation on the format and wisdom of future data collection processes.
- \* The figures provide a starting point which can be confirmed or denied according to data collected locally.

**The figures do not show:**

- \* the different demographic, cultural, social and linguistic elements found in the target community.
- \* what proportion of people identified with a disability are in need of services.
- \* what sort of services are needed.



### **1.2.2. NATIONAL PERSPECTIVE: Locally collected incidence and prevalence data concerning people with communication disorders.**

Research into the incidence and prevalence of people with communication disorders in less developed countries is a new field of study and tends to be impairment related (Pleasanton 1994 Kersner et al 1995). In the absence of locally collected data many locally produced articles and publications resort to using extrapolated data from the more developed countries of the world (Amedofu et al 1993, 1994, Nannyonga-Musoke 1993), as illustrated in the previous section.

National surveys in Nigeria and other less developed countries, on the incidence and prevalence of people with communication disorders, are sparse, poorly documented and therefore difficult to access. Different methods have been utilised but most address the issue non-specifically, through identification of a medical or educational grouping, with very little specific information concerning the proportions within groups who might have communication disorders. The few studies that do target people with communication disorders concentrate on patterns of etiology in relationship to recommended care procedures.

For Example Obiako and Izuora (1983) undertook a two year study of 150 children with 'speech disorders' seen at the University of Nigeria Teaching Hospital between June 1979 and June 1981. Although such a study does not give information about general incidence and prevalence, it confirms that such children do exist in Nigeria and that they have sought help from the medical services.

The results of the study show that a similar variety of causes and degree of impairment, contribute to 'speech disorders' there, as they do in the rest of the world. They describe different kinds of 'speech defects' under mainly physiological headings:

- damage to the central nervous system in 95 cases
- loss of hearing in 42 cases
- damage to organ of speech in 8 cases
- delayed physical development in 3 cases
- psychological factors in 2 cases



This leads to some disparate groupings, for example mental retardation with cerebral palsy, and must have presented complications when deciding where to place children with multifaceted underlying factors. The resulting 'speech disorders' are predominantly either dysarthria or dyslalia which are clearly defined in the paper, but would be difficult to translate into present day perceptions of those terms.

Akapati (1986) argues that the prevalence of 'communication disorders' in developing countries is similar to anywhere in the world. Obiako and Izuora (1983) agree and conclude from their study that the pattern of 'speech defects' in Nigeria is similar to other parts of the world. However they observe that attitudes towards the people concerned differ markedly and comment that :

"whereas the Nigerian Mother starts to worry only when her child's speech disorder is so serious that he cannot communicate verbally, her counterpart in developed countries feels concerned with the slightest deviation from normal.....many parents are unaware that speech defects can be corrected"  
pp 88

Such perceptions will undoubtedly effect any incidence and prevalence studies.

A later more detailed study from Enugu by Iloeje and Izuora (1991) concerning the pattern and prognosis of speech disorders among children expands on the categories of children represented. Of 1105 children with neurological disorders seen in the hospital over a 3 year period 41 boys and 39 girls had 'speech problems'. Dyslalia, defined as something which may be:

"of organic origin. This defect is characteristic of children who have an abnormally large tongue, a cleft palate or those who suffer from malocclusion of the teeth. Also tongue tie caused by an abnormally short lingual frenum restricting the movement of the tongue, is sometimes blamed for articulatory distortion." pp 90.

was still the most common problem, and 32.5% of the 80 children were mentally retarded.

A poor attendance and follow up rate was recorded.

A different approach by Thorburn (1991) reveals a different perspective where 'speech' is listed as a disability type, but it is noted that it is usually secondary to another disability. Here the data show that a 'speech' disability has an overall prevalence rate of 1.3% second only to cognitive disability.



Kersner, M. Mahon, M. and Nzama, S. (1995) recognise the importance and complexity of collecting epidemiological data on 'communication disorders' in developing countries, and that such information is vital

"in order for speech and language therapy provision to meet the needs of children adequately" pp 3

They undertook a survey in Zimbabwe, utilising existing speech and language therapy service provision as recommended by Hartley (1986). The results identify 7,121 children who have a 'communication problem', 3,978 of these children are reported to be receiving special teaching or therapy, while 2,883 are on the waiting list for intervention. They claim these numbers far exceed those reported by the Zimbabwean Ministry of Health in 1992 in a survey that identified 648 people in the category "speech and hearing disability". They suggest that this lower level of identification may be due to a lack of differentiation between adults and children and the use of a less detailed identifying label, i.e. 'speech and hearing disability' in contrast with the comprehensive list of 'communication problems'. The survey shows that the most frequently reported 'communication problem' is one associated with learning disability. They conclude that it is apparent from the study that the need for speech language therapy services supercedes available personnel.

The different parameters of the study by van Amstel et al(1993) which may be more in keeping with the local perception of disability, looked only for the inability to walk, see or hear, excluding other forms of physical disability, intellectual disability and disability as a result of aging which were considered to be inevitable and

"therefore not worthy of serious consideration" pp 317

The results of this study inevitably showed a much reduced prevalence rate, a mere 0.46%, very low in comparison with the estimates from more developed countries.

Puri (1989) reports that in 1960 the Indian government invited Dr. Martin Palmer from USA to study the magnitude of speech and hearing problems in India. According to Puri (1989) based on some surveys, Palmer estimates that 5% of the Indian population require the attention of speech and hearing specialists.



## IMPAIRMENT RELATED STUDIES.

Small surveys, targeting specific client groups offer information which can be useful in incidence and prevalence studies. Such surveys tend to concentrate on groups with a physiological common denominator, such as hearing impairment, physical impairment, mental impairment, and collect information about etiology, severity and demographic factors, (Holborow et al (1982) McPherson et al (1993) Nannyonga-Musoke (1993)). UNESCO (1988) question the relevance of collecting impairment related data as a basis for planning and delivery of educational provision and it is possible that such classification has limited relevance to the development of rehabilitation services.

Saunders and Miles (1990) and Carey (1995) also point out the limitations of such surveys reminding us that:

“Disabilities can only be defined by their context” pp 2  
Saunders and Miles (1990)

“..the least of their problems is the actual impairment..” pp 12 Carey (1995)

They argue that service development should take priority and data should be derived from existing services. They point out that there is also an ethical dilemma concerning locally collected survey data, as it is likely to increase local expectations of service, and this is often not forthcoming. Coleridge (1993) says:

“It scarcely needs pointing out that doing a survey with no follow up or service delivery is a very cruel blow to those identified: a survey raises expectations of a reasonable improvement in their lives and should be done only as part of a general plan for service delivery” pp 109

Publication of service based surveys in less developed countries appears sparse . An example would be Baldwin et al’s (1989) CBR survey at Kibwesi Kenya, but this gives little specific information about people with communication disorders. It is likely that there are a number of unpublished surveys which could give relevant information. For example<sup>in</sup> the unpublished annual report of the Speech and Hearing Clinic of the Special Education Department of the University of Ibadan, Hartley (1982) analyses the nature of the case load in terms of, numbers of clients in different impairment groups, services offered in relation to observed needs, and makes recommendations for future development of the services of the clinic in



consultation with parents families and other professionals. This follows a similar pattern of evaluation as recommended in Rapid rural appraisal by Annett and Rifkin (1995).

In spite of their limitations, impairment related surveys continue to be carried out. Commonly identified groups are cognitive impairment, hearing impairment and physical impairment and in the absence of other data, they do provide some useful information. Information gathered in relation to hearing impairment, because of its close relationship to communication disorders is considered in more detail, to illustrate some of the difficulties and limitations of such studies.

### Hearing Impairment related studies.

A number of studies have been carried out in several African countries into the prevalence of hearing impairment and reported by Hearing Network News of the Hearing and Impairment Research Group (HIRG) in Liverpool. The results of these studies, along with others reported by Hearing Network News can be found in Table 4. It is not easy to calculate how much of the large discrepancy seen in the prevalence levels can be explained by the type of survey used, or the parameters and methods adopted, let alone by true variations of prevalence due to demographic and other local factors.

**Table 4 Incidence and Prevalence studies for hearing impairment in LDCs.**

Date	Country	Age	Prevalence	Reference	Comments
1987	Swaziland	5 - 14	3% mild, 1% moderate and severe	Hearing Impairment Research Group(1992) (HIRG)	Single most important factor otitis media
1992	Gambia	2 - 10	27% severe and profound	Smith and Hatcher (1992)	
1992	Kenya		6% screen failures	HIRG Oct. (1992) Bal & Hatcher	Unilateral 3.7% Bilateral 2.4%
1993	Ghana		8% screen failures	Amedofu (1994)	
1992	Nepal	5 +	16.6%	Hearing Impairment Research Group (HNN) March 1992	prevalence refers to failed screening /earpathology. Conclude 35% preventable. No.1 disability in Nepal.
1993	China		0.18 %	HNN Oct. 1993	severe hearing loss
1992	Aboriginal		15%		Ear pathology
1992 - 3	Namibia	infants	0.6%	Pleasanton	30:1000



Smith and Hatcher (1992) note that researchers have conducted few population based studies on the prevalence of deafness or hearing impairment in sub-saharan Africa, the studies that do exist focus on children attending schools for the deaf or special clinics. They conclude from the various surveys reported, that there are 1.2 million people with moderate to severe hearing loss in Africa and 3.9 million with a mild hearing loss. This would be .3 % and .9% prevalence rate, if they are referring to sub-saharan Africa, a relatively low figure taking into account the higher prevalence rates of causative illnesses such as measles, rubella and meningitis reported by Holborow et al (1982) and Pleasonton (1994). The latter refers to information reported in 'The Namibian' (1994) giving information concerning the number of reported cases of malaria in 1993 as 149,000 and 546 cases of meningitis between October 1993 and April 1994. She hypothesises that this high prevalence, together with the fact that treatment for these diseases frequently involves the use of ototoxic drugs, must result in a larger population of hearing impaired people than would be found in countries where these diseases are rare.

MacWhite (1993) asks if hearing impairment should be measured at all in less developed countries, but Saunders and Miles (1990) feel that the details revealed by these surveys, such as the causes of hearing impairment, provide information which is very valuable to the community where they were conducted, and this information can have positive effects on the planning of a service. The process of searching for people with hearing impairment can also serve to raise the awareness level of that community and identify client groups.

"In most cases the interest engendered by conducting the survey is associated with some change, in Western terms, of services offered, even if this change is not sustainable." pp7

Problems arise when the figures obtained in these small surveys are used to calculate more general incidence and prevalence rates. For example, Bal and Hatcher (1992) found a 6% prevalence rate for hearing impairment in their sample of 5,368 children from the Kiambu district of Kenya. This is significantly different to the estimated figures extrapolated from Enderby and Philipp (1989), but this figure could be used to estimate the size of this population group elsewhere, for example, in England, where it would, according to



locally collected data, be grossly inaccurate. Similarly in Nigeria, where, based on the premise that 40% of the population is under 16, UNESCO (1990.) it would indicate an estimated potential of 2 million children suffering from hearing impairment alone.

Holborow (1982), indicates that a possible 49% of his sample of deaf children had a hearing loss due to technically preventable causes. By combining and comparing these two pieces of information it might therefore be possible to surmise that 980,000 of the estimated 2 million children with hearing impairments in Nigeria had losses due to preventable causes and base an expensive programme of care on this information. Such generalisations are open to many pitfalls, not least, in this case, because demographic differences are not catered for.

As an alternative to specifically related impairment surveys, some studies relate to the services that have developed to assist, such as:

### **Special Education Related Studies**

A survey carried out by the Nigerian Federal Ministry of Education (1986), concentrated on information about registered Institutions offering some form of training to disabled children. It aimed to explore the number of children receiving special education in Nigeria and estimate how many actually required such services. The survey documents the different categories of handicap reported, and tries to evaluate the rate at which services are developing in different states.

In each of the six categories of disability identified by the Federal Ministry of Education, i.e. Auditory, visual, physical, emotional, mental retardation and learning disabilities, one would expect to find a significant percentage of cases with a 'communication impairment', in some categories, such as 'auditory' or 'mental retardation', this is likely to be substantial. There is however no information in the survey documenting this aspect.

**In conclusion :**

- there is limited and inconclusive evidence gathered locally/nationally on the incidence and prevalence of communication disorders in less developed countries.
- the studies that exist are impairment related and generally do not identify people with communication disorders.
- the studies are inadequate and ill-represented.

### **1.2.3. DISABILITY PERSPECTIVE: People with communication disorders viewed as a proportion of the disabled population.**

The third possible way of estimating prevalence data is to combine the process of extrapolation with the use of locally collected data, by considering people with communication disorders as a certain proportion of the group of disabled people. By using estimates generated in more developed countries together with data on disability collected in less developed countries, it should be possible to calculate the number of people likely to have a communication disorder. Internal and external data are amalgamated. These calculations and estimates can be seen in Table 6 on page 57.

In support of the philosophy that people with communication disorders are part of the disabled population, the OPCS (1986) now list 'communication' not 'speech' or 'language' as a separate category of disability. Communication is listed as a primary disability, one of 13 which also include the related fields of hearing, Intellectual functioning and behaviour.



These categories are different to the ones used for gathering information and categorising disabled people in less developed countries. The words ‘disability’, ‘handicap’ and ‘impairment’ are often used indiscriminately and interchangeably with ‘problems’, ‘deficits’ and ‘difficulties’. The eight categories used for collecting data in Mauritius (1983) see table 5, provide a typical example and include three impairment labels, two problem labels, one deficit label, one disability label and one handicap label. Such categorisations lead to the collection of data which cannot be compared to similar studies, as different categories are used together with a different allocation of the disability/impairment/handicaps grouping. In Table 5 below a comparison is made between the categories used in the Mauritian and Malawian National population census exercise both carried out in 1983. It can easily be seen that a comparison of the data they produce is problematic.

**TABLE 5. Comparison of the terms used in the National Surveys of Mauritius and Malawi in 1983**

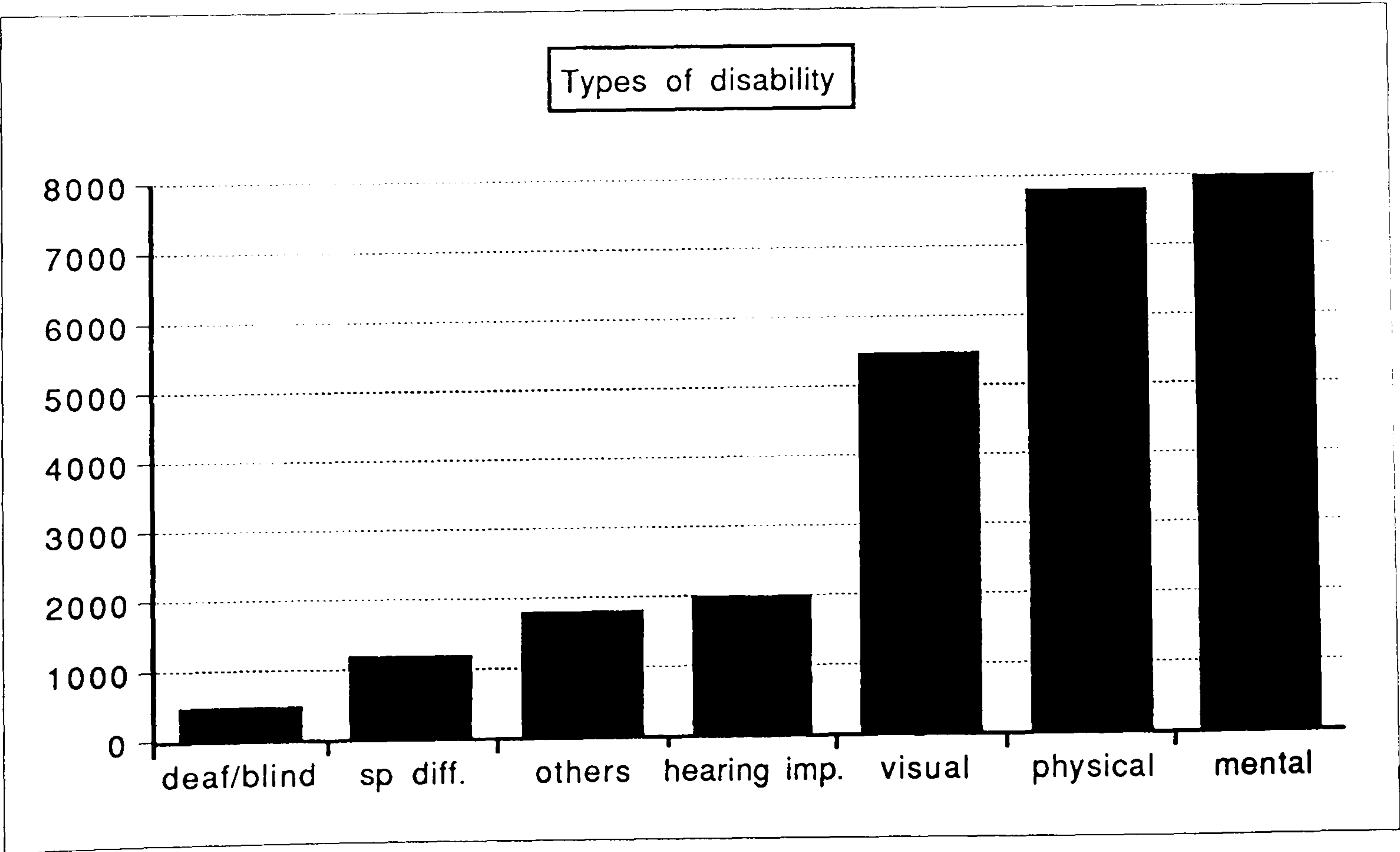
MAURITIUS	MALAWI
Hearing Impairments	Deafness (including pre-lingual)
Visual Impairments	Total or partial loss of sight
Multiple impairments.	Deaf/blind
Movement problems	Crippled limbs
Speech Language Deficits	Speech Difficulties
Mental handicap.	Mental Illness/retardation
Emotional Problems	
Specific Learning disabilities	
	Asthma.
	Fits and Epilepsy
	Other

Neither do these studies help to identify people with communication disorders, as this group of people can be found within many of the categories listed eg. ‘Mental handicap’, ‘hearing impairment’, ‘movement problems’, ‘specific learning disabilities’ as well as the more obvious ‘speech language deficits’.

Disability surveys have been carried out in a number of less developed countries, some are independent studies, eg. Saunders (1984), some are done by Government Ministries, eg. Federal Ministry of Special Education, Nigeria (1986) and some are part of national statistics collection, eg. National Statistics Office, Malawi (1983). The disability prevalence rates which these surveys produce vary considerably, as can be seen in Table 6. As we have already discussed, this is undoubtedly due to different survey methods, definitions and cut off points, as well as to different perceptions and expectations and perhaps even to different prevalence levels.

The studies mentioned, either do not mention communication disorders at all, eg. Federal Ministry of Education, Nigeria (1986), or if they do, the category on 'speech defects' or similar, has a lower prevalence than other impairment groups and does not include many who have communication disorders associated with for instance mental or physical impairment. See Figure 1, an example from the National population census of Mauritius (1983)

Figure 1 Types of disability. Statistics on Disability- Mauritius. (1983)  
(Part of the National Population Census exercise.)





It may be that the cultures in which these studies are carried out do not perceive a lack of ability to communicate as a disability at all, and as Obiako and Izuora's (1983) study shows, parents of children who cannot talk do not show the same level of concern as found in parents from more developed nations. This apparent lack of concern may be due to a lack of awareness and a preoccupation with more life threatening issues. Akpati (1986) suggests that 'perception of need' will be influenced by the limited knowledge concerning disability which is brought about by a high level of illiteracy and lack of exposure to the media within that society.

It seems unlikely that the inability to communicate orally in an African country would be taken lightly, as Mazrui (1986) points out, Julius Nyerere of Tanzania once said that the very origins of African democracy lay in ordinary oral discussion, where decisions are made by talking until issues are agreed upon. Mazrui (1986) also notes that the Africans' reticence to document information may arise from the basic cultural values which refuse to regard the past as a bygone or the present as transient, he says:

"The ancestors are still with us in Africa and we ourselves are would be ancestors" pp 77.

As a result, the oral tradition still thrives today and is apparent at all levels of social functioning. This is particularly noticeable in the modern day Nigerian who still seizes every opportunity, whatever the occasion, for a 'speech', to share ideas, communicate importance, or create an occasion. The high value that Africans generally place on oral skills and the important place which oral transmission of information, ideas and feelings hold, together with low literacy levels secure an importance for communication skills which cannot easily be dispensed with.

It is much more likely that the absence of a 'speech impairment' category for disability is due to the tendency, as reported earlier, for less developed countries to copy the way in which things were done in more developed countries in the 50's and 60's. This may come about through the influence of professionals in missionary and aid programmes, as well as through training nationals from less developed countries in programmes designed for



people from more developed countries. Similar breakdowns of disability categories can be found in the literature of the UK and USA dating from 30-40 years ago (Berry and Eisenson 1962, Van Riper 1963, Morley 1965). This was the time during which many of the present policy makers in less developed countries were educated in the UK or USA. The approach used at that time and illustrated above, overlooks the fact that it is likely that there will be people with communication disorders in many of the disability categories.

A study by Miles, M. (1985b) on children with disabilities in ordinary schools in Pakistan looks at 43,416 pupils attending 103 ordinary schools and identifies 1.9% of the pupils as having a 'perceptible disability', 8% of these had a 'hearing loss' and 32% 'impaired speech'. giving a total of 40% of disabled pupils with a potential risk in the area of communication.

The experience of the researcher over a period of 20 years of setting up services for people with communication disorders in various African Countries, supports Miles's (1985b) observations, and leads to the decision to use a 40% prevalence rate to calculate the likely number of people with communication disorders to be found within the cohort of disabled people. It is appreciated that Miles's research is based on children and that this extrapolation has been applied to a complete population figure, but in the absence of data on proportions of adults with communication disorders in less developed countries this would seem justified.

Comparison of the figures in Table 6 based on Miles's 40% with the figures shown in Tables 3a and b using extrapolated data from the UK, show large discrepancies. (In Nigeria the difference between a possible half a million and 5 million people with communication disorders). This confirms how difficult it is to use extrapolations, and make meaningful comparisons.

However the researcher would argue that the data based on locally collected data is likely to be more accurate and using a disability perspective allows us to access information



which has been collected in the country concerned, this gives a local perspective which has more chance of taking local cultural and demographic aspects into account. It is the process rather than the actual figures which are important here, the process of taking locally collected disability data, to calculate the likely number of persons with a communication disorder, on which can be based plans for appropriate service development.

**Table 6 Calculations of the proportion of a population in less developed countries who may have a communication disorder.**

Country	Age range	Prevalence	Reference	Population Instituto del Tercer Mundo (1993)	No. of disabled people using local prevalence rates	No. people with Comm. disorders using 40% Miles (1985)
Nigeria	5-14 yrs.	1.3 %	Saunders (1990 )	109.170m.	1.4192m.	0.5676m
Tunisia	all	2 %	UN compendium (1990)	7.990m.	0.1598m	0.0639m
Morocco	all	12 %	Chkili (1985)	25.1m	3.012m	1.2048m
Swaziland	all	2.5 %	Central Stats Office Mbaba (1983)	0.760m.	0.019m	0.0076m
Uganda		7 %	UNISE/ Danida	18.442m.	1.290m	0.5163m.
Kenya	0-3 and 3-15	2.8 % and 7 %	SCF/AMREF (1982)	25.393m	1.7775m	0.711m.
Botswana	all	2.2 %	Central Stats Office (1994)	1.285m	0.2827m	0.11308m
Ethiopia		5.5 %	UN compendium (1990 )	46.743m	2.5709m.	1.0283m.
Malawi	all	3 %	National Stats. UNDP/ILO (1983)	8.428m.	0.2528m	0.10113m.

With this in mind, information from the UN Disability Statistics Compendium (1990) covering population census information from 55 countries shows that countries like Peru, Pakistan and Sri-Lanka have disability rate of less than 1% , the UK 14%, whilst Austria claims 21%. Countries in sub-saharan Africa mentioned in the compendium are Swaziland at 2.5%, Zimbabwe at 3.4% and Ethiopia at 5.5%. At first glance these results may seem somewhat puzzling. How is it, one might ask, that a country as advanced as Austria has

such a high percentage of disabled people, when a country like Ethiopia, which lacks stability and medical services has such a low percentage? The explanation for this discrepancy may lie with factors such as a much wider definition of disability in the West, higher expectation levels, a larger aging population with a higher expectation of a continued independent life style. This information gives a clear indication that disability is perceived quite differently in less developed countries and leads towards the realisation that knowing the numbers of people with a 'communication disorder' falls far short of knowing the number of people in need of services or knowing what kind of service they might require.

Coleridge (1993), argues that attitudes and perceptions affect the definitions of disability, as much, if not more, than the impairments themselves. This creates different parameters and result in different prevalence figures . Even allowing for a wide variation in definition, the UN compendium figures clearly contradict the received wisdom that there is a higher proportion of disabled people in developing countries, or that impairment is simply a factor of poverty. In the west a higher survival rate of disabled people and the increased number of the elderly could go some way to explain the tendency illustrated by the UN figures.

DPI (1992) have continued to emphasise the relationship between a disabled individual and his/her environment. This supports the idea that disability is as much the result of the social attitude of a community and the social barriers it raises towards the person with the impairment, as vice versa. As discussed previously, if the handicap resulting from a disability is also a relationship between an individual and his environment, then it would follow that extrapolation of disability rates from one culture to another would be inherently inaccurate and misleading.

Helander (1992) estimates, (see table 7), that disability is an issue which cannot continue to be ignored, the projected increase and sheer size of it is bound to affect countries development and productivity. In his situation analysis for the United Nations Development Programme (UNDP) he makes the following forecasts:



“ the positive effects of prevention will be offset by many other factors that will increase the incidence (of disability) and as people live longer the prevalence will go up.” pp.15

**Table 7. Prevalence of disability(Helander 1992)**

	1993	2025
Less developed countries	183m	435m
Developed regions of the world	93m	138m

His forecasts suggest that the numbers of disabled people will increase by 137% in less developed countries over the next three decades. People with communication disorders will form part of this group, their number will increase over time due to general increases in population and an increase in the perception of disability as the country develops. It is this large and increasing group of people with communication disabilities that need to be identified and for whom services need to be developed.

**1.3.0 SERVICE DELIVERY OPTIONS FOR PEOPLE WITH COMMUNICATION DISORDERS IN LESS DEVELOPED COUNTRIES.**

To encourage the provision of services for people with communication disorders who live in less developed countries, based on a profession specific, individual/medical model, is likely to result in a total denial of service for the majority of the population in need. Given the continually increasing world population and the effect of changing perceptions of disability as countries become more developed, discussed in section 1.2.3., the need for services for people with communication disorders will continue to increase and it is imperative that alternative and appropriate models of service delivery are considered and explored, based on the need identified by the people themselves.

Service delivery should include identification of the aims of the service, detailing the structure, resources and processes and finally measuring the outcomes. Literature concerning this in relation to people with communication disorders in less developed countries was found to be scarce, but articles of a descriptive nature were found within

the pages of the College of Speech and Language Therapists' Bulletin and Newsletters of related professional organisations in other more developed countries. These articles addressed the needs of 'people with communication disorders' and provided an overview in terms of considering such people as an identifiable group. They encompassed all the numerous etiologies involved and described the practical experiences of speech and language therapy professionals in many less developed parts of the world. The information they present is reviewed below and common themes identified and listed at the end of the section.

Cooper and Byers-Brown (1985) began a debate about whether the techniques, including patterns of service delivery developed in the West, were transferable to other less developed parts of the world, or if it was necessary to:

"rediscover the wheel, starting by correcting conspicuous speech defects and only slowly working towards the factors which underpin them". pp 2

Hartley (1986) responded from Nigeria by saying that she felt it was of limited value to transfer Western techniques in the African countries without appropriate adaptation, because of the different:

- cultural values and expectations,
- language usage and structures,
- environments and climates,
- stages of social and educational development.

She believed that with cooperation, flexibility and humility, nations could work together to their mutual advantage, using the underlying principles learnt in the West, together with local knowledge, to develop appropriate training and services. She felt it was a mutually beneficial association but drew attention to:

- the inappropriateness of evaluation, teaching and therapy materials developed in the west for use in less developed countries,
- the importance of recognising and respecting the differences that exist between peoples of different African countries,



- the importance of developing locally based training establishments with support and involvement from 'the top' as well as 'the bottom'.

Subsequent articles have continued to debate these issues, Flicking (July 1985) draws attention to the effect of cultural differences on:

- clinical attendance, which she observed as being poor, due to a different perception of timekeeping together with Muslim Laws restricting Mother's travel.
- different attitudes and expectations relating to school, play and gender
- limited information gained in interviews,

Burland's (1987) descriptive article on her work in Uganda outlines the advantages of the team approach under which she was working. She laments the lack of appropriate evaluation and therapy materials, along with problems created by a lack of linguistic knowledge, information and the technical skills required to keep electronic equipment working.

Swann's (1987) survey on the use of Augmentative and Alternative Communication systems in East Africa and Southern India showed the negative effect of poor economic status, the low priority of the needs of disabled people generally and specifically those with communication disabilities, who were very low on the health and family agenda.

There were numerous cultural implications affecting the implementation of AAC including:

- high expectations of an immediate cure,
- fatalistic notions,
- emphasis on oralism due to tradition and high levels of illiteracy,
- numerous ethnic groups.

Social factors that contributed to a different perception of the situation included:

- poor literacy levels,
- low survival rate of disabled children,

- centrally placed special schools following a western pattern of service
- transport problems.

Swann (1987) concluded that all the factors she raised would affect the assessment, diagnosis and treatment of people with a 'communication disorder' and concluded that disability is very much a functional relationship between the person's impairment and the community in which he exists. She feels there is a need to see 'speech impaired people' within the context of their subculture or community, if any of our western techniques are to be transferred effectively.

House (1988a.b.c.d.) In a series of four articles, leads us through her own learning process starting before her departure to Zimbabwe and her original idea of developing "an exotic new service" through:

- the surprise of finding so many similarities as well as differences,
- working with existing structures,
- realising how much she was learning herself,
- using group activities,
- utilising community involvement and skills,
- appreciating her colleagues input and knowledge,
- respecting local culture.

She uses the knowledge and experience she gains to meet the challenge of adapting western style speech therapy to meet the needs of people with communication disabilities in Zimbabwe.

Sweeny (1988a) in a 'Letter from Fiji' emphasises the importance of;

- training local people,
- the complications of a multilingual society,
- the catastrophic affect of war and political upheaval.

Law (1988) and Marshall (1989) emphasise the importance of international workers having a significant commitment to training if their input is to have a lasting effect,



but Marshall (1989 ) describes some of the practical difficulties that this presents:

- language problems,
- huge pressure to take on a large case load,
- developing appropriate materials and curriculums to meet the needs of the different groups.

In order to try to help therapists planning services in less developed countries Wirz et al (1991) undertook to produce some guidelines. Their advice included:

- the importance of making the service appropriate to the needs of the local people.
- this might involve identifying the needs and then teaching local workers to meet those needs.
- exploration of the different service delivery options
- problems of assessment in other languages and cultures
- the importance of accepting and respecting the local culture.

Hartley (1990) in an article about clinical management of people with communication disabilities identifies the different problems that may present to a clinician when providing services in a less developed country,

- enormous case loads,
- cultural and language differences,
- travelling great distances for help,
- very little, if any, professional support,
- lack of appropriate equipment.

She suggests various strategies that can be used to overcome some of these issues, such as:

- establishing local training programmes
- arranging clinical observation sessions,
- documenting and collecting information about the people seeking help,
- sharing it with the people who need to know,
- working with other professional groups,

- using volunteers and family members,
- flexible hours,
- developing appropriate materials,
- taking a positive view,
- Establishing the idea that people who cannot talk are worthwhile human beings

Law (1991) emphasises the importance of establishing the need before services are introduced, the importance of working with other local colleagues, training and using appropriate technology.

Winterton (1991) describes her work in Nepal and emphasises the importance of teaching, developing appropriate materials and the value and importance of utilising Community Based Rehabilitation programmes.

Amparo Cabello de Neri (1992) explores the possibilities of using the radio to increase public awareness of communication problems in Mexico and describes the content and methods used.

Marshall (1992) observes that in Africa

- awareness of people with 'communication disorders' is poor,
- it receives low priority,
- epidemiological data is scarce and confusing,
- there are very low coverage levels of services given by speech and language therapists,
- if services are to develop appropriately more information is needed.

She explores the factors that contribute to the lack of development of services and identifies the various options open to less developed nations in terms of training speech and language therapists and establishing their services, she questions the desirability of



professionals from more developed countries formulating policies about less developed countries and presents various options in terms of development strategies.

Boothman (1993) describes the involvement of an association for children with language, speech and hearing impairments in Namibia. She reminds us of the important role played by such associations and other professionals involved in services for children who cannot talk.

Bowen (1994) questions whether the skills of a western trained speech and language therapist are appropriate and emphasises the importance of acknowledging and accepting the belief systems and values of the local environment.

Sell et al (1993) and Baker et al (1993) in articles about “Transglobal Therapists” cover reports from Sri Lanka, China, Nepal, Malaysia, Borneo and the Maldives. They:

- give descriptions of counterpart training,
- emphasise the importance of raising awareness,
- emphasise the importance of initiatives coming from the local people,
- the importance of understanding the local culture and customs,
- the importance of training other professionals and families members.

They also draw attention to the incredible benefits that they themselves gained from the experience of working in a less developed country.

Wirt et al (1990) provide a useful impairment based framework for training counterparts in Sri Lanka to help people with cleft palates. They generalise their experience for use in other parts of the less developed world and methodologically highlight some of the difficulties that can be faced when establishing a training programme of this kind. They describe problems of selection, supervision, cultural differences and different education processes affecting teaching methods. How their training programme fits into the established structure of health or education services remains unclear and may be the reason for some of the difficulties they describe.

Hankins and Tonkinson's (1993) study, although not conducted in a less developed country, was carried out in a less developed or underserved area of the UK. They looked at new service initiatives for preschool children in deprived areas of Nottingham. They concluded that deprivation required a community based approach and challenged the medical model, suggesting that a more worthwhile role for speech and language therapists is to become 'enablers', more 'parent centred' and work in cooperation with communities, allowing them to identify their own needs.

In a special issue of ASHA with an international perspective, Wilson (1990) points out that although there is still a long way to go in reaching and providing services for people with a 'communication deficit' in America, other countries often turn to them for advice and support because American services appear to be much more advanced. She observes that people with 'Communication disorders' in less developed countries, understandably, take an even lower priority than they do in America, but that this may, in part, be a reflection of the generally low priority given to this group of people in more developed countries. She argues that speech and language therapy professionals need to do more to put people with 'Communication disorders' on the international agenda with such organisations as WHO. She reports that ASHA's international committee took the initiative of developing guidelines for:

- recruiting overseas students for training,
- conducting basic epidemiologic research,
- establishing cultural specific norms,
- developing culturally specific assessment tools.
- developing better international links with other public service organisations who offer services or have interest in the area of 'Communication disorders',
- the development of a data base so that information can be gathered and more easily shared.



Wilson's (1990) report is accompanied by information on the profession and service development in South Korea, Guam and Micronesia, Soviet Union and China. These stress the importance of:

- raising public awareness,
- developing appropriate standardised tests,
- maintaining professional support,
- developing appropriate training curriculums,
- need for interaction between care providers,
- exchange ideas about training programmes,
- develop new techniques in diagnosis,
- different strategies of patient management
- alternative health care models.

Hammer (1994) in her work with the people of the less developed islands of Micronesia supports Groce's (1990) observations of the importance of cultural context, with specific reference to 'speech and language services'.

Tuomi (1994) outlines some of the problems facing South African Speech and Language Pathologists and the adaptations required of them to function appropriately in the New South Africa if they are to meet the needs of the non-white population. He says that:

"the focus of treatment may need to be shifted from the traditional one-to-one setting....Alternative service delivery models, based on community needs and resources should be implemented. These could rely increasingly on the use of family members, primary caretakers and community based professionals to extend services to areas presently out of reach of the traditional service delivery system." pp 7

In the absence of other data, these articles all use practical clinical experience as a basis for developing ideas and suggestions concerning service delivery options. It is interesting and important to see that there are recurrent themes arising.

They are summarised below:

1. Importance of identifying the local need before commencing the service whether it be a clinical service or a training programme. (Law (1991) Wirz et al (1995) Hankins and Tonkinson (1993) Tuomi (1994) Hammer (1994)).
2. Importance of training local people to meet the identified needs. (Hartley (1986) Winterton (1991) Sweeney (1988) Marshall (1991) Tuomi (1994) Sell et al (1993) Wirt et al (1990)).
3. Importance of developing knowledge and respect for the local cultural customs and values and expertise. (Cooper and Byers Brown (1985) Hartley (1986) Sell et al (1993) Baker et al (1993) Bowen (1994) Tuomi (1994) Hammer (1994) Wirt et al (1990)).
4. Importance of developing a knowledge base, not only of cultural values, but also of linguistic knowledge, local groups and facilities and documenting the information in such a way that it can be easily accessed. (Wilson (1990) Sweeney (1988) Burland (1987) Wirz et al (1991) Tuomi (1994) Hammer (1994)).
5. Importance of developing service structures that are compatible with existing educational, medical and social services. (Hartley (1986), House (1988) Wirt et al (1990) Tuomi(1994)).
6. Importance of realising the limitations of assessment and therapy materials developed by other cultures and assisting in the development of appropriate material if possible. (Hartley (1986) Burland (1987) Marshall (1989) Wirz et al (1991) Hammer (1994)).
7. Importance of working in cooperation and partnership with a team approach, developing mutual respect for all parties involved and appreciating the advantages this brings to both parties. (Hartley (1986) Burland (1987) House (1988) Wirz et al (1991) Hankins and Tonkinson (1993)).



8. Importance of developing long term assistance programmes.(Wilson (1990) Hartley (1986)).

9. Recognising the importance of our role in raising the awareness about people with Communication disabilities(Cabello de Neri (1992) Baker et al(1993) Sell et al (1993), Wilson (1990)), and recognising, but not accepting, the low priority of the needs of disabled people generally and the needs of people with a communication disability specifically. (Swann (1987) Marshall (1991)).

10. Importance of developing appropriate training and service delivery systems by encouraging initiation by local people, rather than superimposing systems from our own country.(Hartley(1986) House (1988) Baker et al (1993) Sell et al (1993)).

11. The importance of seeing 'speech impaired' people within the context of their subculture, whether it be urban or rural, literate or illiterate, etc.(Flicking (1985) Swann (1987)).

12. The importance of utilising community involvement in identifying and meeting the needs of people with a 'communication disorder'.(Winterton (1991) House (1988) Wirt et al (1990) Wirz et al (1991) Hankins and Tonkinson (1993) Tuomi (1994)).

13. Importance of recognising the implications of travelling difficulties.(Hartley (1990) Swann (1987)).

14. Importance of exploring the implications of very low coverage levels with excessively large case loads.(Marshall (1991) Wirz et al (1991) Hartley (1990)).

15. Importance of professional support.(Hartley (1990) Wirz et al (1995) Tuomi (1994)).

Other literature specifically related to service delivery for people with communication disorders was scarce and only a limited number of references were located. Akpati's (1986) overview of issues relating to service delivery for people with 'communication disorders' in 'developing African countries' agrees with Cabello de Neri (1992), Baker et al (1993) Wilson (1990) Swann (1987) Marshall (1991), and alerts us to the effect of different attitudes and beliefs on the perception of such disorders being a disability at all. She says these attitudes are influenced by limited knowledge and awareness as a direct result of illiteracy and limited exposure to the media.

Eldredge's (1993) work with the deaf community of the Australian Aboriginal, however, concludes that this group are considered to be:

"part of a more diverse group of people with a variety of disabilities" pp 21

Pressman and Ruder (1990) in a strategic management plan for 'International Service Delivery' to help guide professionals who are becoming involved with the delivery of services internationally, give consideration to some of the issues highlighted above. They refer to;

'ascertaining the national objectives relating to the development of speech and language pathology and audiology services' pp 48

'formulation of a long term, integrated and focused strategy.... responsive to the recipient country's social development plans' pp 49

'identify particular needs and service options' pp 49

'provide for the communication of pertinent information about the project to national and international institutions' pp 49

thus supporting some of the issue raised by Hartley (1990), House (1988), Tuomi (1994) and Wilson (1990), but giving no indication that the donor may need to learn from the recipient and may benefit from the interaction himself. They make very little mention of the importance of cultural, linguistic and educational issues and their implications on the development plan, and refer to 'standards of training and service' rather than 'appropriate development'. The attitude is patronising and possibly more for the benefit of the professional than others.



In contrast, exploration of literature considering service delivery issues from the disability perspective such as those made by Finkelstein (1989) and Miles (1993) seem to be in agreement with the thoughts and ideas raised by the speech and language therapists, expanding and supporting the observations they make. Finkelstein (1989), himself disabled, takes some of the issues further and questions the wisdom of using the concepts of rehabilitation as a basis or framework for service delivery, he says

“There is growing literature questioning not only the adequacy of service delivery to disabled people but also the appropriateness of some of the basic premises behind these services. The most widely expressed criticism questions the relevance and appropriateness of the medical approaches to the social problems that disabled people face” pp 177

Finkelstein does not identify the “growing literature” he refers to, but Oliver (1990), Coleridge (1993) Helander (1992) O’Toole (1995) are amongst those who make similar observations.

Hurst (1992), another disabled writer, supports and expands this also and says

“We must decide if our goal is to find cures and create technical aids and environments that allow us to function basically as non-disabled people do, or to alter the system so that we can live fulfilled lives as we are -people with disabilities” pp 44

Hurst (1992) has a vision of equality based on interdependence and challenges the professional’s practice of identification with ‘impairment labels’ which she says defines the person in terms of what they lack and denies them what she calls their ‘person hood’. Consideration of such concepts undoubtedly affect any service development plans, particularly as they challenge the impairment based medical concepts which underpin them.

#### 1.4.0. OTHER SERVICE DELIVERY OPTIONS.

In the absence of further literature relating specifically to service delivery for people with communication disorders it was decided to look at information relating to other service delivery options utilised by health, education and social services, and to consider the possible application of these models of service for people with communication disorders.

The rest of this section is structured historically and covers:

- \* information concerning traditional practices,
- \* introduction of the medical model institutions and special education during colonial periods in less developed countries,
- \* various responses made to try and overcome the low coverage levels i.e.. group work, parent, children, family and community involvement,
- \* the introduction of community based rehabilitation as an extension of primary health care and integrated education as a response to the dilemmas of poor coverage and high cost.

#### 1.4.1. TRADITIONAL PRACTICES.

‘Traditional Practices’ are not confined to the activities of traditional healers but also encompass a whole range of activities which are centred on the home and on the community’s response to the disabled person or child. These responses are formulated by attitudes, knowledge and beliefs which are handed down from generation to generation. In order to access information about traditional practices towards people with communication disorders it was necessary to , either, identify them in groups by related impairment etiology, or to consider them as part of the disabled population as a whole. In practice both approaches were used and a range of information describes the underlying attitudes and beliefs about impairments and disabilities which affect the way in which people behave and also influence traditional healing practices.



Mazrui (1986) says that the indigenous belief systems of Africa, unlike those from more developed continents, do not assert a monopoly of the 'soul' for the human species alone; a tree or a mountain may also have a soul and Africans are respectful of other living things. He says that the idea of a force which permeates all nature is evident in many African cultures and these establish a sense of continuity between nature and man and from ancestor to ancestor.

"While the west have a subculture of personal achievement and individualism.. pp 57... in Africa man god and nature are in closest contact, in deepest intimacy." pp 61

Against such a back cloth, it is easier to understand the many spiritual interpretations of disability, described by Mallory et al (1993) and also to develop a realisation and respect for the rich wealth of spiritualism which abounds on the continent of Africa.

Hinckley (1987) quoted by Nicholls (1993) draws attention to the difference in 'western science' (pp 29) and African traditional thought, as the difference between knowledge in terms of an 'impersonal objective world' with that of a 'personal subjective universe'. The implications of this in terms of attitude, expectations, traditions and knowledge are far reaching in all walks of life and the different disability practices which develop from these differing view points, are no exception.

In an ethnographic analysis of traditional healing and rehabilitation services in Southern Africa, Levers and Maki (1994) say that:

"It is difficult for Africans to disassociate from Traditional Healing" pp 80.

According to Levers and Maki (1994) the services of traditional healers are sought routinely throughout Africa and that in certain skill areas traditional healers have a high success rate. Odebiyi (1990) identifies the different categories of traditional healers and their varying roles and contributions and Groce (1990) concludes that the role of Traditional medical healers should not be underestimated. She observes that:

"Traditional healers often answer real needs within their communities, needs which are not always addressed by modern medical and rehabilitation programmes." pp 5



Mupedziswa's (1988) conclusions from his survey, support this, showing that 36% of his sample of disabled people in rural Zimbabwe, went for faith healing before turning to western medicine and also that 62% were still seeking traditional help at the same time as receiving 'western' medical help, are supported by the observations of Jaiyeoba (1988) in Nigeria and by a 'Critical Health' report, (Landsdowne 1991) showing an even higher level of 80% of patients attending traditional healers before going for 'western' help. Lever and Maki (1994), in an extensive literature search found none which addressed the efficacy of traditional practices with regard to disability. Jaiyeoba's (1988) observation that traditional practices are completely community orientated and the need for any health worker to know the culture of the people they care for may explain some of the reason for their popularity and high utilisation levels.

Information concerning details of actual treatment of any of the different types of traditional healers was difficult to come by, but an undated publication of Ibadan University Press by Osifu described herbal treatment of Mental retardation to include the eating of the edible flesh of the boa constrictor and the giant snail 3 or 4 times a day with yam. Interestingly the Yoruba word for the snake is 'lkpin' which is also the local word for Downs syndrome. One can hardly help speculating that a good meal 3-4 times per day must be beneficial when the alternative might be not to waste food on human being with such a limited performance. Herbalist's treatment for a stroke as described by Osifu is one which relates to inadequate blood supply and involves fermentation with hot water to increase the blood supply to affected parts and peppery soup for oral administration, the ingredients of which include a locally produced gin. There is also a recognised connection with this affliction and evil forces which are dealt with by elaborate rituals. Whether people identify the inability to communicate with these 'disorders' remains unclear, the researcher was unable to establish from the literature if there was a different attitude and practice for people with communication disorders.



Searching the literature, some of which is reviewed below, exposes similarities and differences between the more common impairment groups, e.g. physical, mental and sensory impairment, with negative attitudes being more prominent towards people with mental impairment. Whether this negative attitude was related to the inability to communicate, or whether people with communication disabilities are observed as an entity at all, remains unclear, and may vary from place to place.

Adesina and Igbokwe (1989) reported the view that:

“notions regarding physical disabilities and health impairments were closely linked to mysticism, occultism and spirits. These traditional misconceptions..... are similar in terms of attitudes towards handicap among the various ethnic groups in Nigeria.” “..When all efforts at explanation fail, man is left with no choice but to attribute the cause to supernatural powers, and to regard the poor child as an agent of the devil and the angry gods” pp 7

Adesina and Igbokwe (1989) illustrate, with many examples, that the perceptions of Nigerian people towards people with impairments are mainly related to cause. These perceptions vary slightly from impairment to impairment and also according to tribal background, but, according to Adesina and Igbokwe (1989) are surprisingly consistent. The perceptions range from superstitions about the anger of the gods, including, punishments, curses and deliberate handiwork, to ancestors returning to torment the family due to misdeeds. Abang (1988) and Adesina and Ogbokwe (1989) argue that such beliefs create strong negative attitudes, which affect the traditional ways of caring and society's response to the people concerned. This is supported by the observations of Mba (1990) in his description of the reluctant attitude of governments towards the development of education for the deaf. Mba (1990), Adesina and Ogbokwe (1989) and Adebayo (1988), all describe traditional care that can involve anything from total rejection to overprotection. The family are ashamed and often the child is hidden from the view of visitors. Or they may fail to accept or come to terms with the child's disability and expect him to function normally with no help or assistance. Ademokoya (1989) in his survey of parent's attitudes in Oyo State, Nigeria, supports this view, while the work of Ogunboye (1984) Fajemisin (1987) indicates that although both literate and illiterate people have negative attitudes towards disability, there are indications that illiterate people are more



tolerant towards disabled people. Adebayo's (1988) work confirms that education plays an insignificant role in attitudinal formations. A more negative attitude towards those with mental retardation as opposed to other impairment groups, is recorded in the work of Olatunji (1983) and Mojinyinola (1987)

Extreme negative views are described by Miles (1983) who says that in rural Pakistan disabled infants are said to be put to death after birth. This can certainly be corroborated by this researcher's personal experience. While working as a health worker with the Turkana people of Northern Kenya, the researcher observed several occasions when traditional practices were fatal, following circumstances leading to increased chances of disability. For example a baby born after a prolonged labour who, as a result, had a misshapen head, would traditionally be beaten about the head until the head returned to the correct shape. It was not possible to persuade the Grandmothers of that time, who performed this role, to refrain from this and other similar practices. Perhaps as a result, during the two years that this researcher worked in a health dispensary in that area, seeing approximately 100 cases each day, only one child was identified as having a congenital handicap, a Downs syndrome baby of about 9 months.

Groce (1990) believes that knowledge of traditional practices are particularly important when planning community based services and attempts to alert expatriate professionals to this dilemma. This supports the numerous authors quoted in the previous section, who emphasise the importance of knowing and respecting local culture and traditions, when planning and providing services. She says that:

"New programmes must take existing belief systems into consideration and directly address people's beliefs and concerns about disability" pp 2

Unlike Adesina and Ogbokwe (1989), and Nicholls (1993), Groce agrees with Miles (1983) who cautions against making assumptions and argues that:

"No generalisation is possible with regard to the status and situation of disabled people in traditional societies, conditions are too varied." pp 22

Ethnographic analysis by Levers and Maki (1994) supports this and argues that disability is a socially constructed concept which differs in different cultures. Miles (1992) agrees



and points out that in Pakistan, for instance, the people are not exposed to Western media which educates and reinforces attitudes and opinions daily. He argues that these western cultural perceptions may not be as superior as we would like to think and observes that rural people in Pakistan respect their elders, do as they are told and are not used to making their own decisions, whereas it could also be observed that European practices lead to failed marriages, erratic careers, rootlessness and neglect of the elderly.

Murti et al (1995) report on an extensive survey into disability attitudes, beliefs and behaviours (DABB) carried out in Bangladesh, Canada, India and Indonesia which supports this concept. They expect that the variations across the cultures will affect the very meaning of disability itself. They identify the similarities and differences in local attitudes beliefs and behaviours which might affect the future planning of community based rehabilitation programmes and, to aid analysis, they divide beliefs into: internal, external, cosmic and control.

**Internal and external beliefs** about the cause of disability, either accept that it the person's fault due to something the individual did or did not do, or it is due to something outside oneself.

**Cosmic beliefs** lie in the supernatural realm

**Control beliefs** refer to what people think one can do to control the disability.

The results show considerable variation between people in their four survey areas and so they conclude that programmes will need to be tailor made for each community.

Groce (1990) identifies recurring patterns associated with 'cause', similar to those identified by Adesina and Ogbokwe (1989), but also identifies patterns associated with 'expectations', 'social roles' and 'treatment' within the folk medical system. 'Cause beliefs' colour attitude, but in contrast 'expectations' of survival colour levels of neglect and traditional roles, such as begging, and impede change.

There seem to be two main issues arising from this literature, firstly, the importance of knowing and appreciating traditional practice in order to identify needs and formulate



future development of appropriate practice, and secondly to identify and acknowledge good practices within traditional structures so that they can be preserved and encouraged. Traditional practices concerning people with communication disabilities are hard to isolate as very little about this subject appears to have been documented. Akpati (1986) observes that in Nigeria

“Individuals with communication disorders do not enjoy the same consideration in terms of rehabilitation services as those with visible handicaps.” pp 95

However, Miles (1983) describes the security, protection and integration of disabled children into traditional rural life and observes that although disabled persons are stigmatised due to superstitious beliefs,

“On the whole, in most traditional societies, the disabled person is in one way or another integrated into the family community.” pp 11

Kugelmass and Setiono (1991) in their Javan study of Indonesian attitudes towards disability, observed that people rejected their traditional belief systems and this was replaced with a desire to have a ‘western substitute’ due to a lack of appreciation of the value of their own traditional systems.

This may be due to the encouragement given to people from less developed countries to train in more developed countries. Levers, Lopez and Maki (1994) point out that Africans trained in the West, as well as expatriate professionals, seem to systematically deny the cultural validity of the traditional healers. They say that :

“This denial is seemingly reinforced and perpetuated by the rehabilitation services that are emerging and sponsored by donor organisations” pp 80

Nicholls (1993) says that in Africa this lack of faith and self confidence appears to be a direct result of the international mockery of traditional African Ideologies. He argues strongly that there is plenty of evidence to support positive behaviours that are relevant to societies’ response to disabled people and quotes Jacques Maquet (1972) who observes less stress, insecurity and anxiety in traditional African societies, Ndege and Nicholls (1990) who say traditionally old people are treasured and respected, Hinckley (1987)



who describes masks used to portray deformed people used to teach people not to laugh at and ridicule disabled people. Nicholls (1993) describes his own observations in rural Igede, Nigeria, of people, who in spite of their strong traditional beliefs, took a more pragmatic view point, developing a general acceptance of disability. He observes however a higher level of tolerance for disabilities acquired through accidents as opposed to those due to congenital defects.

An interesting study investigating the possible use of CBR in Papua New Guinea by van Amstel et al (1993) says that:

“People with a disability in the highlands of Papua New Guinea seem to find their own solutions to reduce the degree of handicap of their disability and appear to cope reasonably well even in their relatively harsh environment”  
pp 318

van Amstel et al (1993) concludes that traditional practices in this part of the world support people with disabilities, who were well cared for members of the community and that introduction of Community based rehabilitation programmes would be inappropriate. To summarise it would seem that traditional practices are commonly used by people in less developed countries, but the power, influence and subsequent importance of these practices are often overlooked by personnel from more developed countries and also by locals trained in more developed countries. This is mainly because of a lack of knowledge and understanding. The efficacy of such practices with regard to people with disabilities is unknown, although it is acknowledged that in some areas traditional procedures are reported to be successful. Acknowledgment of the role that such practices play in the lives of people in less developed countries is essential, not only for the appropriate adaptation of ‘western’ interventions, as indicated by the review of the literature in previous sections, but also because traditional practices are the basis by which people live all over the world, including people in more, as well as less, developed countries.



### 1.4.2. INDIVIDUAL / MEDICAL MODEL.

The medical model is a type of individual model and was defined briefly in the introductory section of this study. Further exploration and a greater understanding of this prevalent methodology needs to be considered.

To recap, DeJong (1983) says that:

“In the ‘medical model’ the problem is defined in terms of impairment, the solution in intervention by the professional who decides what is the desired outcome for the person with the disability” pp35

Coleridge (1993) expands further by saying:

“ ..the problem with rehabilitation based on the medical model is that it focuses on the individual without relating to the overall social and environmental context” pp 72 and

“ when it is used as the only model for approaching disability, it is seriously defective: based on concepts of ‘normality’ and ‘abnormality’, it sees the human body as flexible and alterable and the social environment as fixed and unalterable.” pp.72.

Finkelstein (1989) comments on the negative implications created by this emphasis on normality and says that

“The aim of returning the individual to normality and eliminating the disability problem is the foundation upon which the whole rehabilitation machine is constructed..... the result can be endless soul destroying hours of exercise trying to approximate able bodied standards..” pp 178

Nevertheless both Coleridge (1993) and Finkelstein (1989) agree that the medical model has certain merits when it is not used in isolation. Coleridge appreciates the role medical professionals have in providing information and choices to disabled people and Finkelstein (1989) recalls his own disability and how much more disabling it would have been without the intervention of the medical professionals. He concludes however that the

“..intrinsic negative implications in the (medical) rehabilitation approach to help have not been properly analysed and understood” pp 179

The medical model of service delivery has been challenged by many people in recent years Helander (1993), Carey (1995) Coleridge (1993) O’Toole (1995) all feel that there is a need for a change in attitude, and that physicians do not have all the answers. They feel that it is important to recognise that there will never be enough professionals, and that the ones that do exist will be urban based, Carey( 1995) says that



"it is more important to bring a small amount of improvement to a large population than to provide the highest standards of care for the privileged few and that the nonprofessional with limited training can provide crucial services." pp 15

Save the Children (1994) refer to

"Specialist Models" pp 61

as being selective, involving professional qualifications, congregated services which are centrally available.

Recommended practice of the RCSLT (Van der Gaag 1996) suggest that services for their client group should be based on information gathered from one, or a combination, of three 'needs based assessment models'. They are:

- disease based assessment,
- client based assessment,
- area based assessment,

All three models are disorder-based, working on establishing the prevalence of specific disorders, either from disease data, client data or area data.

Services for people with communication disorders exported from more developed countries to less developed countries through international personnel, training programmes and recommended guidelines of service and training are most likely to be based on such 'disorder based' delivery models. For instance the desirability of working towards international standards of training is expressed by Lesser (1992) in her international review of training programmes. She regrets the disparity found in the levels and emphasis of the training systems established in different countries and this has led to the development, by The International Association of Logopedics and Phoniatrics (IALP) (1995), of Guidelines for Initial Education in Logopedics. These prepare professionals to function and deliver services within an individual model structure. They advocate disease based assessment with a focus on the need to adapt the disabled person's behaviour.

The model for the development of Special Educational Services exported to less developed countries over the past few decades is also an extension of the individual model, and in spite of attempts to implement integrated or inclusive education the effectiveness of this change in policy, according to UNESCO (1988), is still debatable. UNESCO (1988) reviews the situation of special education based on replies from 58 countries. The majority of these are less developed countries, 17 of them in Africa. The aims of special education stated in this document are predominantly child centred, the emphasis is on identification of 'handicap' and helping the child to overcome the 'handicap'. Policy statements concentrate on the individual child and promoting independence. In other words it is the child who is expected to change and he is identified by his impairment. Even Integration is seen as a problem for individual pupils rather than something which affects the entire education system and the report comments that:

"Integration is a token gesture" pp 12

" Examples of effective participation by parents can be cited but they are far from common place." pp 13

"It is clear from the responses that practice fell short of the ideal of parents as partners." pp 1

#### **1.4.3. INSTITUTION BASED REHABILITATION.**

Institution Based Rehabilitation enables professionals and experts to see a greater number of children that need, perhaps among other things, their specific skills and knowledge. It provides a focus for knowledge and information which, on the whole, has been fiercely protected to ensure the Institution's survival and provide peer professional support and as Van Leer (1986) observes,

'There will always be some people who see a need for institution based programmes' pp 8.

Its limitations evolve around its inability to share knowledge, the development of malpractice behind closed doors, the isolation of the inmates from the community and viceversa, and the disempowerment issues associated with caring and being cared for. One of the limitations highlighted by Kamwendo (1989) from Malawi, in her discussion about the potential limitations of Institutionalised care for children of preschool age with mental handicap, specifically mentions speech difficulties and lack of understanding. She highlights



the problems of isolation from the family in terms of love, care, language and traditions and the limitations presented by only having other inmates to talk to due to the shortage of staff. She recommends better distribution of modified assessments, using institutions on a daily basis so as to avoid separation from Mother, admitting more severe cases on short term basis to give help and relief to families, more staff, and less costly projects.

Institutions all over the world, developed out of the charity model and philanthropists' and missionaries' desire to help handicapped and disadvantaged children and adults. With the development of community services, and evidence of malpractices in institutions, legislation in more developed countries is rapidly bringing to an end the era of the institution.

The CBR training manual WHO (1989), however, reminds us that in some less developed countries there are no rehabilitation services at all, but in many others the only provision may be institution based . On the whole these serve very few people, an estimated 2-3% (O'Toole 1991). But it would seem wise to heed the message of Livian Njini a former resident of a Jairos Jiri Institution in Zimbabwe, quoted by House et al (1990), who says it will take a long time to persuade people that institutions are not the only way of helping people with disabilities, in spite of the fact that they reach such a small number of the people in need and as McConkey (1995) points out, it is arguable that there will always be a place for them in providing care for the very severely disabled people of our communities.

Since the advent of CBR in less developed countries, institutions have continued to offer services; this is not usually in competition with community services, but where there is little, if any, alternative available. Their efforts have been much criticised by service planners and western experts (Helander 1993).

Miles(1993) draws attention to the advantages gained from utilising a central location which can provide a focus for training, information gathering and sharing, as well as opportunity and protection for very severely disabled people. He argues that institutions

have a role to play which cannot easily be met by CBR programmes and agrees with developmental activists, Jaffer and Jaffer, who according to Miles (1993) remark that:

“the need for institutions is a vital factor missed by CBR ideologies.” pp 114

Ironically, Helander (1993), recommends that permanent structures be set up by CBR programmes, for awareness building and knowledge and skills dissemination. He indicates that a role could be played by existing institutions, complementing the CBR services. De Carpentier (1994) accepts this challenge for the Holy Land Institute for the Deaf in Jordan and, in describing the role of institutions in community based rehabilitation and what he calls community based special education, he concludes that this is an enriching and mutually beneficial exercise.

#### **1.4.4. FAMILY/PARENT INVOLVEMENT.**

The importance of the role of parents and the family in the remediation of children specifically with ‘communication disorders’ is stressed by Rustin (1995) in her overview of the related literature and is supported at a general level by McConkey (1985) who says:

“The involvement of the child’s family as an active participant is critical to the success of any intervention programme..” pp 20

There is plenty of evidence to suggest, (Ayer 1984, Mc Conkey 1985, Van Leer, 1986) that parents seek services which reinforce rather than replace their efforts, but in reality the parent’s role and involvement in the rehabilitation of their disabled child has often been overlooked and under utilised (UNESCO 1988). The implementation of parent programmes has evolved slowly in the history of special education and rehabilitation and as Kugelmass (1990) says,

“often with a good deal of resistance from the professionals and hesitation on the part of parents.” pp 1

He concludes that professional services have a tendency to overlook the fact that parents are the prime care givers of their own children.



Cunningham and Davies (1985) describe the development of

- the 'expert model' where the professional is dominant and concentrates on promoting the child's functional status,

- 'the transplant model' in which the role of the professional is seen as training the parent to promote the child's functional status and

- the 'partnership model' which promotes a working relationship between the parent and professional using negotiation and joint decision making.

They describe the process by which these models have developed over time, increasingly acknowledging the expertise of the parents but highlighting the need for using different models at different stages of intervention.

House et al (1990) and Bean and Thorburn (1995), describe services in Zimbabwe and Jamaica that place great emphasis on parents playing a central role in the rehabilitation process. They say that utilisation of parents skills, and the time and commitment they are prepared to make, is a resource which is often under appreciated. The model used by Victor (1995), of ecological mapping, strongly supports the importance of the role of the parent and family of a child and shows clearly how the child is embedded within social systems and the important position, in his world, of the relationship with his family.

Ng'andu S.K. in Serpell (1989) challenges the possibility of outreach services and argues that although they may be desirable, they place impossible expectations on many families and parents. She analyses the home environment into which children with severe Mental Handicap are born in rural Zambia. She observes a need to educate parents in child care and management, to include primary school teachers to work with parents in partnership. But she also observes that there is no hard data on coping mechanisms of families in rural areas and there is a tendency to assume that Mentally handicapped people are comfortably provided for. She says that the present integration of Western family patterns and the breakdown of the traditional extended family by education and urbanisation, is threatening the extended family and the burden is falling on the Grandparents.

van Leer (1986) says that :

"Whether parents are indeed prime educators is not a debatable issue, the question is what support systems are needed for them to discharge their role?" pp 11

Various possibilities are discussed in the following sections.



## PARENT GUIDANCE

The term 'parent guidance' has been used by many professionals involved with children who had hearing impairments, Nolan (1988) McCracken and Sutherland (1991), to refer to their relationship with the parent. They recognised the need to 'train' parents to help their children, if the 'oral' method of rehabilitation was to be successful. The term reflected the perception that they were 'in charge' and leading the parent. The value of this approach was recommended by McPherson (1985) and Holborow (1982) in Gambia and Nigeria, when they, among others, recommended its usefulness for meeting the vast needs of people in less developed countries where services were scarce. A similar thrust took place in recommendations concerning stimulation and care of intellectually impaired children (McConkey 1985; O'Toole 1995; Mittler 1986).

Initially the parent's role was a subordinate one, but Mittler's UNESCO paper 'Working Together' Mittler (1986), Kuitert (1989) and Mittler (1990), served to emphasise the value of parent involvement and parents became the key performers. As a result of the increased interest in the role of parents, several initiatives have developed. They are considered below.

## DEVELOPMENT OF GUIDES AND MANUALS.

Several guides or manuals have been developed for use with parents in less developed countries. Initially these were locally developed and rarely published, but eventually it was observed that much time could be saved and standards improved by sharing information. The guidelines have been 'impairment related' and often 'country specific' eg. Peace Corps (1985) for hearing impaired in St. Lucia. From this start the WHO took the initiative recently to publish more universally applicable guidelines in association with the World Federation of Occupational Therapist and the World Confederation of Physical Therapists, WHO (1993). These guidelines are still impairment specific, i.e.. cerebral palsy and prevention of deformities in polio, but represent an awareness of the different cultural issues which need to be considered and communicate clearly the present 'state of the art' information for other workers to share.



The hardest task for internationally developed material is to design information that is culturally sensitive and appropriate. Internationally developed material can easily be patronising and dependent on Western concepts of disability. This can either be through the influence of international personnel or nationals who have trained in western establishments and have abandoned their own cultural base and adopted 'western' ideals.

### **SELF HELP GROUPS.**

Self help groups involving parents as a method of service delivery have naturally led to the development of parent groups. These have in turn led on to 'self help' parent groups. This process has been complementary to the development of CBR and self help groups of disabled people and responds to the very low coverage levels achieved by more conventional methods of intervention which, according to Helander (1993), reach under 3% of disabled people who need rehabilitation. The skills needed to set up self help groups, whether they be parents or disabled people themselves have been encouraged and enabled by information gathered and distributed by the United Nations (1990a). Armstrong (1993) comments that there are now self help groups in all parts of the developing world.

Laurent (1989) explores the idea of parents helping parents. He advocates home training to parents and volunteers on how to apply low cost, simple intervention techniques and how to work with community service providers in developing multi-disciplinary coordination. There is no specific mention in his work of children with communication disabilities.

### **CHILD TO CHILD.**

'Child to Child' as described by Bonait and Hawes (1992) is an approach to Health Education introduced in 1978, following the Alma Alta declaration on PHC, prior to the International Year of Disabled children in 1980/81. It supports and encourages children to spread health ideas and practices to other children, both able and disabled, and to parents, families and communities. It includes initiatives involving children with disabilities generally and children who do not hear or see well specifically. This approach has been popular and able to maintain the flexibility required to respond to the differing needs.



## PARENTS AS PARTNERS

Seeing and using parents as partners is the latest perception, Mittler (1995) argues that as parents are closest to children in every way, professional efforts are most effective if directed towards supporting the parents. He also feels that parents and teachers have information about the child which need to be shared. In exploring how best to nurture a partnership he highlights the importance of respect, a right and need to be informed, the opportunity for making contacts, involving parents in professional training, professional meetings and policy makers..

Mittler (1986) says that :

“What we have learned from the early intervention project throughout the world is that programmes that have involved parents and families have consistently achieved better outcomes for children” pp 7

He believes these strategies can work but the implementation is still at an early stage of development and points out that:

“although there is universal commitment to the principles of partnerships with parents... practice frequently lags behind”  
pp 7. Mittler (1986)

van Leer (1986) agrees that the relationship between professionals and parents should be one of partnership, their roles being complementary and not hierarchical. He warns against the professional taking a superior position and ‘teaching’ the parent.

It would seem that this warning often goes unheeded, and in spite of the ideals, the reality of the situation appears to be a different story. In a survey by UNESCO (1988) information from 70 countries was collected and evaluated, there were many examples of parents feeling under-involved and uninformed. The survey laments the poor implementation of parent involvement in special educational development.

Kugelmass (1990) describes an Indonesian system of caring for children with mental handicap in West Java by family adaptation, where the goal is to establish services by families not for families. Many of his observations would seem relevant to African society. His study examines how societies, who have not yet embraced technology and



professionalism as a cultural ideology or tradition, try to meet the needs of mentally handicapped children. It seems the families interviewed rely more on an informal support network, religious beliefs and the extended family for emotional support than on the educational or medical professional. However, he reports that as these families are exposed to western civilisation they begin to doubt the value of their traditional approaches towards caring for one another, they want institutions to care for their disabled family members and the all knowing and powerful 'spiritual doctor' is being replaced by the 'western physician' who also knows best and should be obeyed. Ironically the development of health and educational services in western civilisations have found it necessary to develop government regulations which statutorily involve parents in the planning of programmes for their children but they still encounter difficulties with implementation. This seems to be because with the Western development, comes a belief in science and technology. Institutions, specialisation and professionalism are accepted as a traditional component of western civilisation and serve the larger ideology impeding the development of a balanced partnership. Kugelmass (1990) concludes that

"The avoidance of the 'non-rational' elements in both healing and caring that has been continually reinforced by the great tradition in our society that rests on the belief in the scientific and technical solutions to human needs must be challenged critically if we are to provide optimal care for children and their families" pp 36.

O'Toole (1989) observes that societies with poorly developed health and education services, where traditionally, the responsibility for the upbringing and education of the child still rests unchallenged on the shoulders of the parents, a healthier attitude, without dependency on outside agencies, exists. O'Toole (1989) comments that the most creative examples of parent-professional partnerships have come from the poorest nations.

In a session on 'Parents as Partners' at the World Conference on Special Educational Needs in Salamanca, UNESCO (1994) speakers raised the following issues:

- the need to use the potential of parents and families in working in partnership with teachers and other professionals.



- parents are the first experts on their child and it is time to start talking about professionals as partners rather than the reverse.
- the key for co-operation is mutual respect and acceptance
- professionals need training in learning to listen to parents
- inclusive schools should employ a coordinated service delivery model.

An example of using parents as partners in less developed countries can be found in the special education programme of Uganda reported by Wadidi (1994), who discusses strategies about developing a partnership between teachers and parents. The issue presents ideas for helping all impairment categories, reports on a sign language seminar, how to make play dough and other games, self help skills for blind children and descriptions of family support centres, there are, however, no contributions from parents and the attitude of the publication is one of the expert addressing the person needing help.

#### **1.4.5. COMMUNITY BASED REHABILITATION (CBR)**

O'Toole(1995) summarises the aim of CBR as

“CBR’s goal is to demystify the rehabilitation process and give respectability back to the family and the community” pp 85

But as Mendis (1992) points out, the overwhelming strength of CBR is that it provides the vehicle for developing services as documented by the United Nations (1983) World Programme of Action Concerning disabled persons, by providing a frame work which allows the disabled person to remain within their own community, make decisions, receive assistance within the regular structures of education health and social services and be able to take an active part in their own social environment.

As we have already discussed in the introductory section, the concept and implementation of CBR varies considerably. Much of the literature, Thomas (1990) Miles(1989) O'Toole (1995) Zinkin and McConachie (1995), while drawing attention to the differences in implementation, also highlight the major contribution that the WHO has made in establishing



CBR, and the influence of its training manual WHO(1989). However, according to Pupulin (1992), although the WHO has promoted CBR for almost 20 years and sees CBR as an integral part of PHC, the WHO's role is one of advice and support, and it does not undertake to work directly with local communities. The irony and contradiction of WHO promoting Community Based Rehabilitation when by its own definition it should be instigated by local people has caused embarrassment and also modification of its own definitions.

### DIFFERENT MODELS OF CBR.

Miles (1993a) says that CBR has been used and understood by different people to mean several different things and cites several examples:

1. Therapeutic measures applied by families
2. Self help projects of a therapeutic, educational, vocational or social nature, organised by people with disabilities.
3. A broad ideology whereby allocation of resources are centrally planned and equitably allocated.
4. Projects in which rehabilitation institutions or disability resource centres take knowledge and skills to rural or deprived communities.

Miles explains that in the late 1970's WHO would have liked to introduce CBR with meaning 3. but, in order to persuade countries to participate, had to sponsor projects more in keeping with 1 and 2. This tended to be counter productive to the spread of meaning 3, thus the confusion developed.

Momm et al (1993) feels that CBR would gain more credibility if it were based on the worst scenario and addressed specific social and economic issues in the context of each community. They argue that it exists in two forms:

\* Based on the model of grass roots Public Health Programmes, rehabilitation was simplified to the extreme to allow even the illiterate community member to carry out therapeutic exercises and produce simple aids and devices. It is entirely non-institutional.

\* An extension service based on the objective of bringing professional rehabilitation services to larger numbers of disabled people particularly in rural areas, and to refer people in need of more sophisticated services such as available in rehabilitation centres.

Kisanji (1995) takes this idea a step further and explains the advantages of considering the variations of CBR as different models, giving examples of

- \*professional approaches in Zimbabwe
- \*Location based approaches in Uganda and Zimbabwe
- \*Programme origin approaches in Kenya, Swaziland and Zimbabwe
- \*Community participation approaches in Kenya
- \*the CBR worker approaches in Kenya.

He feels that models are a useful way of classifying CBR programmes and allow us to look at programmes in a consistent way helping us to understand how and why they work.

## IMPLEMENTATION OF CBR.

Many countries have taken on the development of CBR programmes as small scale pilot programmes, usually with the help of International or National NGO's. These programmes have limited and varying degrees of community involvement particularly in the initial stages. A summary of some of the CBR Programmes found in different African countries can be found in Table 8. Note that the only example of CBR found in Nigeria is an ILO sponsored project for Vocational Community based rehabilitation. A description of this programme can be found in the situational analysis in Chapter 2.

The style and emphasis of programmes differ according to their origins, benefactors, and level of community involvement. Susie Miles at a Save the Children Fund global seminar in April 1994, (Save the Children Fund 1994) reports that in 1987, rehabilitation programmes in Southern Africa followed the principles of Primary Health Care and applied rehabilitation



**Table 8. Examples of CBR programmes in Africa**

COUNTRY	YEAR STARTED	SUPPORTED BY	COMMENTS	REFERENCE
Benin	Jan 1990	UNDP Pilot scheme	Coordinated by Helander, UNDP and NGOs Terre des Hommes and Medecins sans-Frontiers	Gerber (1992)
Botswana	Jan 1985	Red Cross initiation	Mid-term evaluation reported: *generally successful *need more prof. staff	Unpublished Red Cross report
Ghana	1987	Salvation Army	Integrated Nationwide programme	Med. Bulletin August 1987
Gambia	1989	Red Cross		Mendy (1993)
Kenya	1982	Action Aid AMREF SCF	Review in 1990	Baldwin, S. Asindua, S. Stanfield, P
Lesotho	1981	SCF	Projects in Lesotho Scott Hosp. (SCF) Majara Community Centre (Les.Gov) Quthing Mobile (Danish) Mahobong ha Lesiamo (private)	Miles, S (1991).
Malawi	July 1989	UNDP/ILO	Initiated in seven districts evaluation reported to be positive	Malawi Council for the handicapped (1991)
Mozambique	1991	SCF	Emphasis on social intervention rather than medical intervention	Miles, S. Medi, E. (1994)
Namibia	1992	Ministry of Health/Oxfam	Problems identified *not enough experienced staff *poor job descriptions *negative attitudes	Nghatanga and Lang (1993)
Nigeria	1990	ILO/UNDP	Community based vocational rehabilitation programme *very small numbers *difficulty with implementing turnover	Federal Ministry of culture and social welfare UNDP/ILO
South Africa	1990	Part of PHC programme Pre-prog.	Based on qualitative need analysis. Training developed	Cornielje, H Ferrinho, P. (1990)

with the medical model of disability prevailing. Emphasis was on 'rehabilitation' rather than 'community development'. She goes on to describe a profound change in CBR, from one of certainty with medical model emphasis on rehabilitation and service delivery as an end in itself, towards a strong emphasis on community development, collaboration and commitment to influencing policy and changing attitudes. This was done, she says, by liaising with committees of people who had few medical rehabilitation skills, but who focused more on education and employment issues, so that disability was seen as a development and political issue.

Miles, Asindua and Carey, in SCF (1994) felt that the interest was changing direction, from service provision to seeing disability as a social/economic and political issue and that disability was not something that was limited to health.

M. Miles (1993b) suggests that now the WHO's plan for CBR is getting simpler and more realistic and there is open recognition of its relationship to PHC, (Pupulin 1992), it would be sensible for CBR to learn from the PHC experience and use information, observations and evaluations of PHC practices. He particularly thinks that the following PHC experiences might be relevant for CBR development practices:

- “\* the most effective plans are based on a knowledge of what positive resources actually exist in a given community...
- real things get done round key local individuals...
- \* rural community leaders, if consulted may not want CBR at all, or may give it low priority.....
- \* discover what ordinary people really want, how much they would do to achieve it....
- \* Grass roots workers.... will usually want some technique, some quick successes that will promote their status...” pp 239.

Jobert's (1985) observations of Community Health Workers in India would support Miles as he concludes that there was little reflection concerning whether the services offered were actually what the people wanted and needed.



## **CBR AND SPEECH AND LANGUAGE THERAPY.**

A specific example of the development of CBR in relationship to speech and language therapy is described by Aron et al (1992) who, in 1984, responded to the urgent need to extend the scope and delivery of speech-language and hearing therapy services into community based projects by developing a diploma course for 'Community speech and hearing therapists'. This training had a firm base of rehabilitative practices within a primary health care model and was a pioneer of innovative thought when it was introduced. However the training and subsequent development of service, failed to accommodate the existing service structure and by its mere existence and the absence of similar training in the other therapy fields, it gave an over emphasis to the speech and hearing aspect of rehabilitation. This made it difficult to accommodate the more generic services which developed. However the development of this training provided the first move towards basing a service on meeting the needs of the people with communication disabilities in a less developed country and the lessons learnt provide the basis for the observations and challenges made by Tuomi (1994) discussed in 1.3.

## **CBR AND EVALUATION.**

Evaluation of CBR has been problematic as O'Toole (1987) points out, evaluations to that date were in-house WHO evaluations with assumptions and subjective methodology which were questionable. Momm and Konig (1989) in discussing the development of what they term 'community-integration programmes' which might be considered by others just be yet another example of CBR, summarise their observations on CBR programmes by concluding that CBR has serious shortcomings as it is professionally unsatisfactory, difficult to organise and establish self sustainability and not feasible without major back up from outside the community. Their perception of Community-Integration programmes sees involvement of disabled people and community resources as key factors which they argue are not generally present in CBR Programmes.

Realistic evaluation of their effectiveness is problematic given the different parameters of each project but in comparing rural and urban CBR programmes in Kenya Asindua (1995) concludes:

- \* Community participation is easier to achieve in the rural rather than urban CBR programme
- \* Lifestyles in urban areas are more disrupted and irregular than the relative stability of the rural areas, but in rural areas women have heavy work loads leaving less time for community activities.
- \* Home visiting in towns is much easier than in rural areas due to the proximity of the houses and better public transport.
- \* Collaboration between the agencies involved is much harder in Nairobi and there is often competition; in rural areas collaboration tends to be easier to achieve.
- \* Advocacy in rural areas is difficult to achieve because of the lack of role models, in the city there are problems because of the different perceptions of need advocated by the disabled elite.

#### **1.4.6. INFORMATION BASED REHABILITATION**

Miles (1993 b) identifies information based rehabilitation as a strategy that he feels can meet the needs of a great number of mildly and moderately disabled people, who at the moment have little or no access to services or information. He argues that service providers wish to spread sufficient knowledge and skills to enable disabled people to improve their quality of life. He feels that this is more feasible than changing the attitudes of whole societies, which would seem to be a prerequisite for CBR if it is to succeed. He advocates utilising the concepts of Information Based Rehabilitation as an interim measure and facilitator for the social change, required if implementation of CBR is to take place.

Miles (1993 b) argues that the information needed to make real change in the lives of the majority of disabled people is now known in Institutions, but the challenge is to distribute it to the masses who have many different levels of concept and understanding. He feels



that the future organisation of rehabilitation services will involve many different ways of doing this but that Information Based Rehabilitation sees the complementary nature of all strategies. Miles (1990b).

Miles (1993 b) argues that information is stored and transmitted:

“inefficiently, inconveniently and expensively in cities” pp 110

He feels that by organising information which may start as being

“bits and pieces” pp 110

into: - concepts: ideas, attitudes and beliefs.....

- knowledge: whatever people know,....

- skills: learnt from practical experience and modified appropriately

- designs: application of the concepts knowledge and skills.

People can be made aware that there are things that they can do themselves. He concludes that:

“The successful transfer of knowledge across cultural boundaries requires more than translation of language and ‘cultural adaptation, conceptual shifts are also needed. Concepts knowledge and skills combine in producing design, whether of drugs, wheelchairs, sign language or training packages” pp 239.

#### 1.4.7. INCLUSIVE / INTEGRATED EDUCATION

The universal declaration of human rights in 1948 proclaiming the right of everyone to education started movement towards integration and participation. Championed by Mittler, P. Mittler, H. and McConachie, H. (1986) Mittler, P. (1993), the quest for expansion and a renewed vision of basic education prompted UNESCO and UNICEF to launch their joint project “Education for all: Making it work” in UNESCO/UNICEF (1990) they agreed that a policy of ‘more of the same’ would not be sufficient to achieve the goal of ‘education for all’. They recognised the need for fresh ideas and a broader vision of how basic learning needs could be met along with the courage to turn this vision into practice.

Little (1992) says that the realisation of ‘education for all’ as outlined by the world conference depends on the resolution of four critical tensions . The first is between lending financial resources and lending ideas and practices, the second between learning for all



and the selection of a few, the third between external standards and internal cultures and the fourth is between system level reform and classroom level reform.

Mittler (1993) says that:

"In countries where a significant number of children do not attend any form of school, or drop out after three or four years, the issues of integrated education for disabled children have to be seen in a wider perspective... reaching the unreached is therefore the major challenge for the rest of the decade and for the 21 st. century." pp 8

The World Conference on special needs education held in Salamanca, Spain in 1994, UNESCO (1994) gathered together many 'experts' in the field in order to develop policies, increase understanding and perspectives, and produce a working document. The resulting Salamanca declaration concludes that:

"Integrated Education and community based rehabilitation represent complementary and mutually supportive approaches to serving those with special needs. Both are based upon the principle of inclusion, integration and participation and represent well tested and cost-effective approaches to promoting equality of access for those with special educational needs as part of a nationwide strategy aimed at achieving education for all" pp 65

Practical implementation of integrated education for children with special needs in countries where a large proportion of children, for a variety of reasons, do not have access to any, or very little schooling, might be considered premature and impractical. However as Mittler (1993) points out, 'Mainstreaming for all' might be more relevant to children in developing countries where the

"...day to day concerns of a family with a disabled child centre around the necessity of food and drink, beliefs and superstitions of neighbours about disability and their inability to secure a school place for their child." pp 9

It would seem important to consider what advice is being given by aid and support programmes. Is the advice based on experience of living there and knowing something of the local social systems, the peoples' attitudes and values, needs and wants, or is it a superimposed from our own culture? Mittler (1993) says that:



"In countries where the majority of non-disabled children are not attending school, it is not surprising that parents are likely to press for special schools, run either by themselves or with the support of public or private funds. .... Even countries committed to integration have argued the need for a small numbers of well resourced special schools, to provide specialist services, a place where teachers can be trained and a base from which children can be integrated..."pp.10

In an action study on the integration of handicapped children in schools, Miles (1985b) reports that in many less developed countries integration already occurs without any fuss, this is often due to a lack of diagnosis and lower expectation levels together with a more pragmatic attitude.

Delegates at the SCF (1994) conference report that integrated education follows the normal curriculum as closely as possible in Lesotho and Kenya. Mamonyane Mohale said that in rural Lesotho informal education was more appropriate than integrated education but that in urban areas both were needed. She felt it was very important that the education they received should be able to equip them for life.

Evidence of examples of Integrated Education in African countries is listed in table 9 below:

**Table 9. Evidence of integrated education in two African countries.**

COUNTRY	REFERENCE	SUPPORTED BY	COMMENTS
Lesotho	Miles, S. (1991)	SCF	3 egs. described. *Leseli Community Centre *Thaba Tseka (Min of Ed) *Mphatlatsane Comm School
Zimbabwe	House, H. (1990)	CIIR	Reports gradual move away from segregated education to integrated education, discuss factors such as *cost *coverage *better adjustment for child and family *need for flexible response *Institutions need to accept challenge too.

#### 1.4.8. EVALUATION.

Evaluation is a topic in itself which has been well researched. The extensive literature related to this field will not be reviewed in this section, which intends to limit its observations to evaluation as an integral part of service delivery.

Coleridge (1993) and Saunders and Miles (1990a) argue that there is a need for service delivery to include evaluation within its framework, so that models of delivery can be flexible and respond appropriately to changing needs and cultural and linguistic forces.

Save the Children (1994) have evaluation processes built in to the development of training recommendations, on the basis that workers need to be trained to meet the needs of the people they are serving and not simply deliver services according to personal skills or interest. They also identify the importance of sharing and distributing the information which is gathered, so that workers and recipients can benefit from the information.

Mittler (1986) says that obstacles which impede implementation of existing knowledge cannot always be blamed on a shortage of money or poor government decisions, but are often related to:

- the way in which knowledge and information is communicated, interpreted and applied.
- the service structure and its organisation.
- professional hierarchies and the way they communicate.

He concludes that in future evaluation strategies must concern themselves with organisational structures and processes if:

“we are to arrive at a better understanding of achieving social change through the application of knowledge” pp 547

Mittler (1993) points out that to monitor a service requires:

- the aims and philosophies of the service to be identified and recorded.
- development of criteria to permit comparison between aims and achievements.
- development of procedures for feed back.



He argues that while independent evaluation may have some advantages it can often pose problems for the collection of accurate data which tends to be qualitative in nature, and not easily accessible to 'strangers' . At the same time results may be resented by service providers and there may be greater value to encouraging them to do the evaluation themselves. This may facilitate more effective feed back into the service structure and create greater understanding and higher sensitivity to the issues raised.

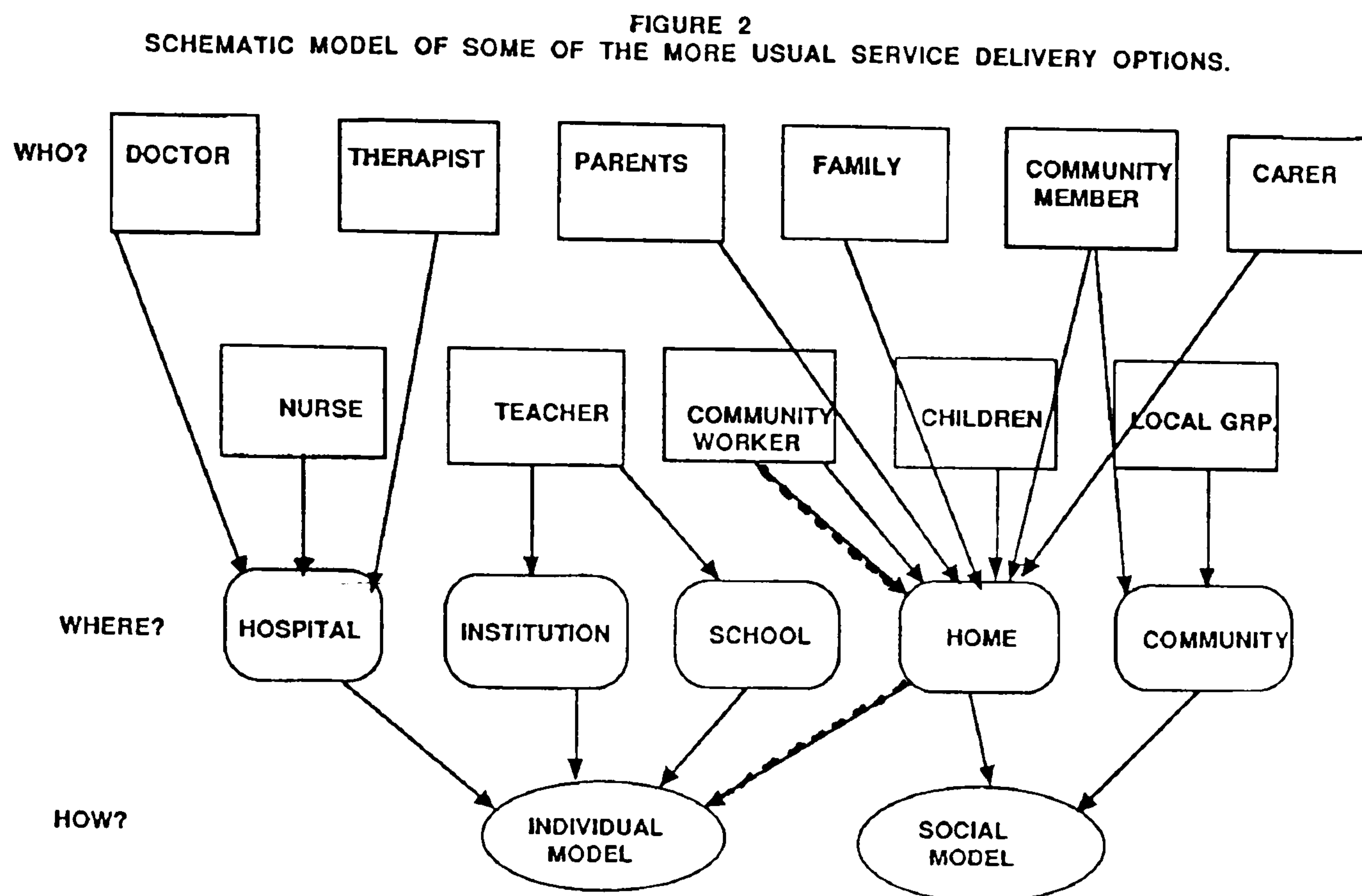
The importance of evaluation as part of the service delivery process is recognised by Saunders and Miles (1990 ), Thorburn (1991) and also by the WHO in its development of guidelines for rapid participatory appraisal to assess community health needs (Annett and Rifkin 1995). The guidelines are designed to help managers collect data to build up information for developing and maintaining a plan of action. Rapid appraisal looks at ways of quickly collecting data about:

- community needs, structures and involvement.
- physical and socioeconomic environment
- availability of health, environmental and social services
- government and municipal health policy.

and using this information as a basis for planning and subsequent evaluations and modifications.

The literature reviewed in this section has considered different parameters of service delivery in terms of who? where? and how? eg. doctors to family members, hospitals to homesteads, individual model intervention to social model intervention. Some of the usual avenues of relationship are illustrated in the schematic model in Figure 2. However the researcher observed from the literature that these avenues are not a foregone conclusion and the person or place is not necessarily the determining factor controlling the manner of service delivery, as one might initially suppose. An automatic connection between the medical/individual model with doctors and hospitals, and the social model with community workers and the community based approach should be questioned. In reality, and demonstrated very clearly in the CBR video promoting a community based approach by McConkey et al (1990), community workers are quite capable of delivering services

at a community level with an individual/ medical model approach, this relationship is shown on the model with a dotted red line.



#### 1.5.0. SUMMARY OF KEY ISSUES

##### RELATING TO SERVICE DELIVERY MODELS FROM LITERATURE REVIEW.

- \* The use of medical terminology reinforces the medical/individual model
- \* The disparity of terminology between professions leads to misunderstanding and confusion.
- \* New, descriptive terms need clarification.
- \* Knowledge concerning Traditional Practices is under-reported in accessible literature. As a result it is undervalued and underutilised, both by western intervention and by locally developed policies and practices.
- \* There are a significant number of people with communication disorders in less developed countries. These numbers are likely to increase with socioeconomic improvements and the resulting changes in perception.



- \* Present day services for people with communication disorders in less developed countries have very low coverage levels.
- \* The use of the disability model allowed access to a range of information which seemed to be relevant and useful when considering people with communication disorders.
- \* It is important that disabled people themselves are involved in the planning of services at all levels.
- \* Observations based on the clinical practice of Speech and Language Therapists in less developed countries give practical confirmation supporting many of the theories of disability research eg. community participation, identification of needs, utilisation of families etc.
- \* There is awareness that interventions based on partnerships with parents are more beneficial but there is often a reluctance to follow this line of action.
- \* It is suggested that categories of impairment have limited relevance to the planning and delivery of educational provision. This may apply to services for people with communication disorders.
- \* There seem to be serious questions raised and dissatisfaction expressed, as to whether the professional model can meet the wants and needs of the disabled person.
- \* The literature makes assumptions about the connection between 'doctors' and the 'medical/individual' model, and 'community workers' and the 'social model' which are not always born out in reality. There is evidence that both individual and social models of service delivery can be found in all venues and delivered by all the different types of people involved.
- \* Services seem to be based more on professional skills and interests than identified wants and needs.

## CHAPTER 2. SITUATION ANALYSIS OF SERVICE PROVISION FOR PEOPLE WITH COMMUNICATION DISORDERS IN OLD OYO STATE, NIGERIA.

*Go in search of your people,  
Love them,  
Plan with them,  
Serve them,  
Begin with what they know  
Build on what they have  
But on the best of leaders  
When their task is accomplished  
Their work is done  
The people all remark  
We have done it ourselves.*

*James Yen 1930*

### 2.1.0. INTRODUCTION

As a strategy to compensate for the lack of previous studies and reported information, it was decided to carry out a situation analysis of services for people with communication disorders. The aim was to gather and document relevant information and then to use this together with the literature review to generate questions for investigation and discussion, thereby ensuring that the direction of the investigation was in response to the reality of the situation, and not initiated solely from theoretical knowledge generated on another continent.

#### **Nigeria was chosen as the country for analysis because:**

- the researcher had several years experience of working and living there,
- she had developed working and trusted relationships with many Nigerian people involved with services for people with communication disabilities,
- this gave access to information, attitudes and beliefs which would otherwise have been difficult to obtain,
- the people of Nigeria form about 1/5 of the population of the continent, approximately 1/4 of the population of sub-Saharan Africa, and just under 1/2 of the population of anglophone Africa. They are therefore representational of a large proportion of the people in Africa, (see Table 10).



**Methodology used for the situation analysis:**

- utilization of documentation such as local reports, letters, government policies
- interviews with policy makers and service providers- Ethnographic background
- meetings and discussions with Nigerians from a variety of backgrounds, e.g. Scientists, drivers, caterers, agriculturalists, clerical workers.

**Table 10. Population of Africa, sub-Saharan Africa, Anglophone Africa, Nigeria, Kenya and Lesotho. According to figures published by The Third World Guide 93/94, based on the most recent UN estimates.**

Areas	Total population	% of total	% sub-Saharan	% anglophone
All Africa	530.9 m.			
Sub-Saharan	415.0 m.	78%		
Anglophone	242.3 m	45%	58.3%	
Nigeria	109.2 m.	20.5%	26.3%	45%
Kenya	24.5 m.	4.6%	5.9%	10.1%
Lesotho	1.8 m.	0.33%	0.43%	0.74%

Old Oyo State was chosen for the purposes of the situation analysis. Oyo is a south westerly state, occupied predominantly by Yoruba speaking people. The State boasts the oldest University in the country, and the first one to have special education programmes. It is likely that the facilities in Oyo state relating to special education are more developed, than in for example, states in the north. In comparison with other states, Oyo has reasonable transport infrastructure which allows communication and movement within the state at a more acceptable level than in other areas. However population pressures are high, and what Oyo may gain from a longer history of development, it may lose in larger scale implementation problems.



# NIGERIA

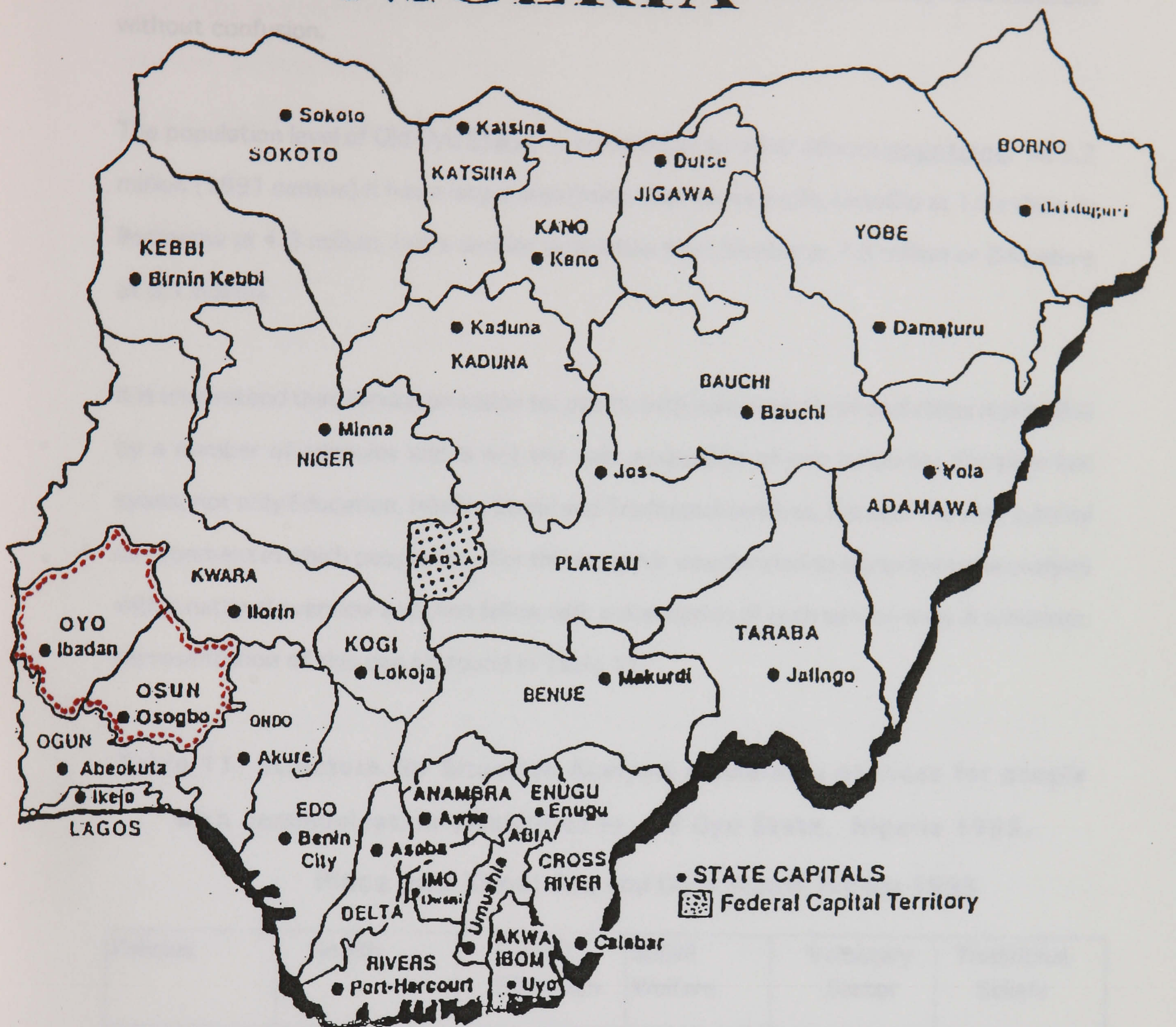


Figure 3. Map of Nigeria. (Nigerian Information Services 1992)

The decision to locate the situation analysis in Oyo state coincided with a directive from the Federal Government in 1993 to create several additional states. This was an attempt by the Government at creating more manageable units. Old Oyo state was divided into two states, new Oyo State and Osun State. Inquiries and observations made six months after this division, indicated that there was still uncertainty and confusion about the demarcations of responsibility and in practice the management and structure had changed very little . It was therefore decided that for the purpose of this study the area of both Oyo and Osun States, would be



used, in other words the “old Oyo State”. It’s location can be seen in Figure 3 on page 106. Identification of the old boundaries allowed the use of previous surveys and statistics without confusion.

The population level of Old Oyo **State** is comparable to other African **countries**. At 5.7 million (1991 census) it has a larger population than for example, Lesotho at 1.8 million or Botswana at 1.3 million, but a smaller population than Zambia at 7.8 million or Zimbabwe at 9.1 million.

It is understood that service provision for people with communication disabilities is provided by a number of agencies and is not the sole possession of one particular discipline but spans, not only Education, Health, Social and Traditional services, but also the very cultural environment in which people live. For this reason it was decided to commence the analysis with a national overview and then follow with a description of each service area. A schematic representation of this can be found in Table 11.

**Table 11    Structure for Situation Analysis concerning services for people with communication disabilities in    old Oyo State,    Nigeria 1993.**

**Place and Time: Oyo and Osun States, Nigeria 1993**

Policies	Health	Special Education	Social Welfare	Voluntary Sector	Traditional Beliefs
Infrastructure	Hospitals Health Centres CBR	Specal Schools Regular Schools Training	Institutions Home visiting CBR	Special Schools Homes Mission Work	Social Structure Implication of beliefs
Services	Specialist Professional in Hospital	Speech and Language Therapy in schools	Counseling Home visiting Financial Assistance	Sp. Therapy in Special Schools and homes. Services in mission hospitals	Specific Action relevant to people with communication disorders
Staffing	Doctors, nurses PHC workers Therapists	Special Teachers	Social Workers	Philanthropist Nurses Teachers Doctors Therapists Managers	Families Communities Local people

Input into Training

The researcher, having lived and worked in Nigeria for over a period of 12 years, used knowledge and understanding gained during that period, and collected information in an informal, participatory and ethnographic way, structuring it as far as possible according to the schematic plan outlined in Table 11.

### **Limitations.**

It was not possible to give all the sections equal attention due to very difficult working situations at that time, caused by strikes, local unrest and political friction. Material for the section on social services was seriously curtailed and information about traditional services even more difficult to obtain. This was mainly due to the danger and difficulty of travelling in the more remote areas. The section on traditional beliefs is known to have been collected from a less representative sample of informants for these reasons, but it is included because of the valuable data collected and its relevance to the study.

Occasionally references are made to situations in other Nigerian States. This is either in the absence of information about the subject in Old Oyo State or because it is felt that the information is relevant to the situation in Oyo and adds an important perspective. At the end of each section there is a summary of the implications for establishing services for people with communication disorders which arise from the information gathered.

### **2.2.0. NATIONAL OVERVIEW OF BACKGROUND INFORMATION.**

Any public service, including one for people with communication disorders, needs to be viewed in <sup>the</sup> context of the environment and its people. Not until this perspective is established can real meaning be attached to the facts and facilities which have developed, or should be pursued.

### **2.2.1. HISTORICAL PERSPECTIVE.**

The early phases of Nigerian history are reflected in a series of important civilizations, described under section 2.2.6. Nigeria, as it is known today, can be traced back to the influence of contact with western systems and cultures from the end of the last century.



### 2.2.2. GOVERNMENT AND ADMINISTRATION.

Prior to contact with the western culture the peoples of Nigeria were governed by the senior members of their own tribal groups in what seems like a form of inherited dictatorship. Their physical boundaries were fluid and of a tribal and linguistic nature.

The earliest contact between the peoples of Nigeria and the peoples of Europe were mainly commercial. Initially these contacts were with the Portuguese. Contact with British traders and missionaries later marked the beginning of British colonization. In the north of Nigeria Arabic influence was much older, but not colonial in nature, having evolved from the ancient trade routes across the Sahara.

Formal colonial rule began when Lord Lugard took over administration from the Royal Niger Company in 1900. Subsequently the territory was administered as three separate protectorates, but in 1914 they were merged and Nigeria was born. After the second world war the demand for self government culminated in independence in October 1960.

Six years after independence the civilian administration was replaced in a coup d'état. Over the next ten years constitutional developments resulted in an increase in the number of states from four to 11 before the outbreak of the Biafran civil war. Subsequently in response to local demands in 1975, 19 states were identified. In 1979, a constitution based on the presidential system with an executive Head of State was introduced. This form of government remained in place with minor modification to reflect the military rule which was reintroduced at the end of 1983, but in April 1989, President Babangida formed a new constitution based on a report submitted by the Constituent Assembly. This initiated a phased transition designed to return the country to civilian administration in January 1993. Elections were successfully held for all state legislative positions culminating in a delayed Presidential election in August 1993. Despite international approval and recognition for the election, the results were declared null and void by President Babangida prior to handing over to a nominated civilian President and cabinet selected by the armed forces ruling council. Amongst

the resulting turmoil in 1994, General Sunni Abacha, a member of this cabinet, took over power and declared himself President. He claims to be working towards implementation of civilian rule in 1998.

In 1992 The Federal Republic of Nigeria was divided into 30 States, (old Oyo State was divided into new Oyo State and Osun State), the new Federal Capital area of Abuja and 500 local councils.

### **2.2.3. GEOGRAPHY AND CLIMATE.**

Nigeria is one of the largest countries in Africa, covering an area of 923,768 square kilometres. The country lies along the Gulf of Guinea on the West African coast. It is flanked on the west by the Republic of Benin, on the north by the republic of Niger and on the East by the Republic of Cameroon. These boundaries are a relatively recent creation. In spite of hills rivers and plateau areas, no major natural boundaries exist, apart from the Atlantic ocean to the south. The terrain is often difficult, with forests and swamps on the southern zone, using rivers and their tributaries as natural arteries of communication.

The climate varies from tropical in the coastal area with heavy rainfall, to sub-tropical in the north. The vegetation profile varies from coastal mangrove swamp and tropical rain forest to Savannah. Semi-desert conditions also exist in the far north. These distinct geographical and climatic zones largely dictate the flora and fauna of the area. There are two principal seasons, the dry season from November to March, and the rainy season from April to October.

The temperature in the coastal areas rarely rises above 30 degrees Centigrade, but humidity can reach 95%. Inland, the climate is drier and temperatures range from 20°C to 36 °C.



2.2.4. DEMOGRAPHY,

The population of Nigeria has been estimated at 120 million, but in 1991 the Nigerian census figures claimed this to be an overestimation and 88.5 million was the official figure released to the press. Breakdown of these population figures for Oyo and Osun States for male /female proportion as published at the time can be seen in Table 12 .

Up till now (1996) no further details of the population breakdown have been published from the census, yet the Nigerian Population Commission has continued to receive a substantial budget for its operation, for example its budget in 1993 it was N191.993 million (£1 = c.45N) Nduilor (1993).

**Table 12 Population figures for Oyo and Osun States for males and females taken from the 1991 census figures published by The Daily Sketch, Akandi (1992)**

State	Males	Females	Total
Osun	1,079,424	1,123,592	2,203,016
Oyo	1,745,720	1,743 ,069	3,488,789
Old Oyo State	2,825,144	2,866,661	5,691,805
Nigeria	44,544,531	43,969,970	88,514,501

There has also been much dissension reported in the press concerning the accuracy of the figures so far released. Nwankwo (1992), for example, points out that the population figure for Oyo State of 3,488,789 includes an estimate of 400,000 people for Ibadan city, whereas a report of the UN Water Project Commission states that there are one million habitable structures in the same area and the Ministry of Education, one million children registered in the schools in the city. It is obviously not possible for all these estimates to be correct and a number of States have taken the Government to Court disputing the figures because their State budgets are related to the population size. Recent correspondence, August 1995, with the United Nations Population Fund Country

Director re-affirms that the 1991 census data has yet to be released and is apparently still waiting personal clearance from the President. The present estimated population for Nigeria is considered to be 109,170,000 (Third World Guide 1994).

#### **2.2.5. ECONOMY.**

The country has considerable mineral and agricultural resources. These include oil, gas, tobacco, palm products, peanuts, cotton Soya beans and rubber. Dissatisfaction concerning the management and distribution of this wealth is reflected daily in the National Newspapers, The Guardian, The Daily Sketch, The Sunday Republic and others.

#### **2.2.6. CULTURE.**

Nigeria is famous for its ethnic diversity, which has greatly enhanced its cultural heritage dating back to the early Stone Age.

- \* About 500 BC, the Nok culture evolved. This is represented by Terra-cotta figures fashioned with great sophistication and other cultural elements.
- \* The Igbo Ukwu bronze casting culture was discovered in 1938 when staff heads crown breast plates, pendant ornaments, anklets and chains dating from the 9th century were excavated.
- \* Similarly the Ife culture, noted for its bronzes and terracottas, also flourished from the 9th century.
- \* The Benin bronze casting culture, which produced Nigeria's best known works of art, emerged around 1400 AD lasting as late as the 19th century.
- \* Other notable works of Art including glass pottery, weaving and wood carving are characteristic of various parts of the country. Nigeria has contemporary skilled sculptors and many famous writers and musicians , and in 1977 hosted the second World Black Festival of Arts and Culture which has provided immense resource material on African Culture.



### 2.2.7. THE PEOPLES OF NIGERIA.

Nigeria is a land inhabited by various peoples of different ethnic origin and culture. Their ancestors have now been settled in the area today known as Nigeria for many centuries. In spite of their obvious diversities the peoples of Nigeria share much in common. According to the Federal Ministry of Information (1990), they share a number of traits arising from similar traditions, value systems, behaviour patterns and beliefs. The Oral tradition, for example is very strong in Nigeria and is not only used for passing information attitudes and beliefs from one generation to another but also forms the basis of a kind of national identity. Great store is placed on a person's ability to speak in public and even the smallest event will be graced by long speeches from all concerned. The different ethnic groups are not confined by the arbitrary borders originally established in colonial times, but often spread over two or three modern day countries, this produces conflicting cultural identity with many examples of different linguistic and religious cultures within the same geographical area, conflicting concepts of nationalism and difficulty with tribal unity. According to Akande (1993), it is estimated that as many as 250 ethnic groups exist in Nigeria today, each with their own language. The three largest of these are Hausa, Yoruba and Ibo.

The Hausa speaking tribes occupy a broad area spread over Sokoto, Kaduna and Kano States as well as part of Niger, and Hausa is spoken in many parts of Nigeria's other northern States, as well as in the northern parts of Ghana, Benin Republic, Togo and in most parts of the Niger Republic, which has a predominantly Hausa population. The bond of the same language, customs and traditions between people of the same tribe is a strong one, and often surmounts national loyalties, making it difficult to develop national pride and unification.

The Yoruba speaking peoples occupy a large area of south-western Nigeria and part of the neighbouring Benin Republic. The Yoruba, whose culture reflects a considerable degree of sophistication, trace their origins to the secret city of Ile Ife, which has since remained the spiritual centre for Yorubaland, and which is renowned for the artistic perfection of its bronze sculptures. Yoruba culture is molded on the intricate interrelation of religious and social rites, with the activities of men being perceived as interconnected with those of the

unseen world and visa-versa. So strong are the Yoruba cultural beliefs that they have survived in many other parts of the world where the Yoruba have settled.

The Ibo speaking peoples of eastern Nigeria are the nations third largest ethnic group. They do not have the same traditions of kingship or a heritage of centralized political institutions as do the Yoruba and the Hausa, but are nevertheless known for having a rich and dynamic culture of considerable complexity based on lineage, (Federal Ministry of Information 1990).

#### **2.2.8. TRADITIONAL RELIGIONS.**

Indigenous Nigerian religious beliefs and practices offer an illustration of the underlying unity that characterizes the traditions of the country. Imasogie (1985) says that Nigerians share a belief in the existence of a 'Supreme Being', known as Olurun or Olodumare among the Yoruba, Chineka among the Ibo, Obassi among the Efik, to name but a few. Although the 'Supreme Being' is conceived as being omnipresent and omniscient, he is not ordinarily thought of as being involved in human affairs, but as belonging to a sphere too exalted to permit intercourse with mankind. Hence the recourse to lesser divinities having power of intervention, such as the earth divinity, Ala of the Ibo speaking people, or Shango the Yoruba deity associated with thunder and lightning. In addition to divinities, other categories of spirit beings are also believed to exist, and the Kalabari of the Niger Delta for instance make a distinction between water spirits and the spirits of the dead. According to Imasogie (1985) Traditional Nigerian religions usually coexist peacefully with other major religions of non-Nigerian origin which have developed large followings in modern times

European contact with Nigeria resulted in the introduction of various denominations of the Christian faith to the people of Nigeria as early as the 16th century, but it was not until the mid-nineteenth century that increasing European contact with Nigeria brought a new wave of Christian missionaries in the country. Many of these missionaries are remembered



for their humanitarian and medical contributions. Although there is still some controversy over the degree to which the Christian missions may have facilitated British domination in Nigeria, there is no doubt that the various churches have made considerable contributions to the development of modern Nigeria through their schools, hospitals and medical centres. In Nigeria today, the different religions coexist reasonably peacefully when they are not being used politically, and along side traditional beliefs. Revival Christian sects such as the Cherubin and Seraphin church have gained large numbers of new converts by injecting an indigenous aspect into church rituals and ceremonies.

#### **2.2.9. LIFESTYLES AND CUSTOMS.**

Beginning with the elaborate ceremonies that follow child birth, nearly all Nigerians become involved with a life long cycle of traditional ceremonies that mark important events in their life, culminating in the final funeral rites that signal the end of their passage on earth. In most Nigerian communities, the birth of a child, especially of the male sex, is an occasion of great rejoicing. The actual naming ceremony of the child is of great importance, as it represents its formal introduction into society, not unlike a christening used to be perceived in our own culture. During the course of the ceremony it is common for small quantities of significant food to be touched to the child's lips and body, as a symbolic foundation for its journey through life.

Among Nigerians, marriage is also nearly always preceded by elaborate betrothal ceremonies, even where the final ceremony takes place according to Moslem and Christian rites. Traditionally polygamy was widely practised in Nigeria, and still remains the norm in many communities. Among Muslims, for instance, four wives are permitted, while it is traditionally accepted among Nigerian peoples that polygamy is natural and conducive to social harmony. Monogamy is increasingly accepted now as a result of exposure to western culture, but there is no stigma attached to children who are born out of wedlock. Much emphasis is placed among Nigerians on family ties, so that extended family groupings are the norm in Nigeria, especially in the rural setting. This is greatly facilitated by the

traditional mode of architecture, which tends to consist of household units in which a common courtyard is shared by related members of the same family. Communal solidarity and mutual interdependence is ingrained in Nigerian tradition, and so even the very poor are rarely completely destitute. Unfortunately such positive aspects of Nigerian traditional culture have now been seriously jeopardized by the relentless pressures of modern city life, although family and communal solidarity, still remain essential for the great majority of Nigerians.

Nigeria's present day infra-structure teeters on the edge of total chaos with erratic and almost non-existent water and electricity supplies even in the wealthiest areas of the cities, virtually no public transport or railway services operating, poor and unreliable telephone communication, with schools and hospitals regularly closed or on strike. Daily management of this chaos involves making extra payments for every commodity or service required. This practice is observed by the international community as corruption.

#### **2.2.10. EDUCATION.**

##### **TRADITIONAL AFRICAN EDUCATION.**

African Society considered education as a means to an end. Functionalism was its main guiding principle. The end objective is to produce an individual who is honest, respectable, skilled, co-operative and conforms to the social order of the day. Fafunwa (1991) describes the seven cardinal goals of this approach which he says are consistent throughout the different ethnic groups and societies in Africa and can be identified as:

- i To develop the child's latent skills.
- ii To develop character.
- iii To promote respect for elders and those in position of authority.
- iv To develop intellectual skills.
- v To acquire specific vocational training and to develop a healthy attitude towards honest labour.



- vi To develop a sense of belonging and to participate actively in family and community affairs.
- vii To understand, appreciate and promote the cultural heritage of the community at large.

It was, and is, a participatory type of education, the children learn by doing. There is 'continuous assessment' which eventually culminates in a 'passing out ceremony' or initiation into adulthood.

Traditional Education is often criticized because of its limited goals and also because it is geared to meet the basic needs of the child within a restricted environment. The critics also contend that it does not train the child to challenge or change those aspects which are unprogressive within the system. A. Babs Fafunwa (1991) points out however, that many modern systems of education only pay lip service to education as a means of effecting desirable change, and concludes that the strength or weakness of any system can best be judged by the relative happiness of the masses of people who go through it.

## **HISTORY OF MODERN EDUCATION IN AFRICA.**

The missions without exception used education as a means of conversion; the Methodists, Presbyterians, Roman Catholics and Anglicans all firmly established themselves in the area. The Colonial Government made spasmodic attempts to assist some of the missionaries in their educational work by giving grants and scholarships but only in 1882 when an ordinance based on the British Education Act of 1844 was implemented did the Government have an official role. In the early 1900, with the establishment of Nigeria as a British Protectorate, government schools began to be established, but it was not until 1925 that the British Government had a clearly defined policy on education. The policy paper was a complete adoption of a report by Phelps-Stokes on education in Africa published in 1922, Fafunwa (1991). Basically, this attempted to control the quality of education and prevent mushrooming of poor quality schools, and to recognize the importance of creating an educational curriculum which was appropriate to the culture and needs of the people.

In practice, present day education is fraught with many more serious difficulties involving pay and conditions of service for the teachers themselves. Directives from the Federal Government increased their pay but the local State governments who pay them were not given the money to do so. The result has been wide spread strikes and closures which in some areas of the past year has resulted in schools not functioning for more than half the year ( Laval 1993) .

### **HISTORY OF SPECIAL EDUCATION.**

In Nigeria, as in many developing countries of Africa, Special Education began informally with the care of children identified as “ handicapped “ by Christian Missionaries. Mba (1991) reports that in Nigeria the first children identified in this way were “physically handicapped”. This early effort was prompted by the need to provide some form of training for children and adults who had been disabled by leprosy, thus the first educational programme for the physically handicapped was established in 1914 by Baptist Missionaries, the first school for the blind in 1940 by the ‘Church Missionary Society’, and the first School for the deaf in 1956 by the ‘Society for the Care of the Deaf’.

In terms of Government involvement in Special Education, the earliest law in Nigeria that mentions educational provision for what they refer to as “the handicapped”, was the Lagos Education Act of 1957 which merely called for establishment of Special Education in Lagos State, if and when necessary. Other laws were The Northern Nigerian Education Law of 1964 and the Western Region Law which laid down that special schools might be established if the Ministry of Education considered it necessary. Direct Government involvement began on October 1st. 1974 with a pronouncement from the then Head of State that henceforth the Government would make adequate provisions for the education and care of the handicapped(Mba 1991). Following this statement, the Federal Government College of Special Education was established in Oyo in 1977 and a Special Education section of the Federal Ministry came into being. Scholarships were awarded for students to study special education at Ibadan and Jos Universities and also abroad. It was at this



point that the number of special schools for ‘the handicapped’ increased considerably. 1977 was also the year in which the National Policy on Education was formulated, with its section on Special Education. A great deal of impetus also came from The Nigerian Educational Research Council, a group of professionals who initiated a number of workshops, seminars, publications to demonstrate the value of special education to the people of Nigeria.

#### **2.2.11. IMPLICATIONS FOR THE DEVELOPMENT OF SERVICES FOR PEOPLE WITH COMMUNICATION DISORDERS.**

- The Nigerian people are proud of an old and established history demonstrating a highly skilled ancestry which was well developed at a time when “western countries” had very little civilization. The people of the country want respect and recognition for this ancestry and do not accept “advice” easily, particularly from those who do not have an understanding of their background and perceptions. This has obvious implications for service development when initiated or supported by “westerners” or “western” ideas.
- The mixture of ethnic pride and western education which has been produced by sending students overseas, can result in difficult and conflicting ideals. For instance, the western concept of rehabilitation is based on promoting independence where the traditional Nigerian social structure places much more emphasis and value on interdependence.
- The country has suffered a great deal of political chaos since independence and has been unable to sustain civilian rule for any length of time. This results in uncertainty, repression, insecurity and a lack of self determination which affect all services in the country. There seems little indication that this will end.
- The lack of accountability and political stability hampers the development of services at State or Government levels as illustrated by the ‘census mess’, annulled elections, huge defence budgets etc.

- The development of smaller states has taken a step towards establishing more manageable units which should help the development of services in the years to come.
- Management of chaos, so often to be found in Nigeria's streets, shops, businesses and government, leads people to resort to any method of "making things work". Such activities, often referred to as "corruption" by western society are seen as a daily necessity if an end result is required. This also has obvious implications for service development.
- The confusion that results between the division of Federal and State Provision provides a loophole which is often used for the misallocation of funds and confusion of responsibility, as shown clearly in the 1992-93 teacher's pay dispute.
- The huge geographical diversity of Nigeria has implications for travel and communication difficulties which affect all services in the country.
- The excessive humidity and heat of the country does not foster exertion of the national and visitor alike, especially in the absence of appropriate architecture or reliable infrastructure to maintain air-conditioning.
- The large population, see Table 12. Page 111, poses problems which other African countries do not have to face. Services continually crumble under the onerous demands of too many consumers, whether it be for water or electricity, transport, road space or food supplies.
- The people of Nigeria know that their country has wealth in the form of many natural resources. On the whole these resources are underutilized and, where they are realized the wealth seems to find its way into the hands of the few. This results in a high level of frustration amongst the ordinary people.



- The Ethnic and cultural diversity found in the country results in many tribal conflicts and a lack of national cohesiveness which also has implications for service development.
- Two hundred and fifty predominantly oral languages, do not serve to simplify the task in hand!
- The diversity and fervour of religious beliefs can, on the one hand, provide a platform from which services can develop, but on the other tend to support the “charity” model of “care” which can be detrimental to the development of “enabling” and “empowering” people to help themselves.
- The lifestyles and customs followed by particular groups are essential information for developing an understanding and knowledge of the people who require services and this information must be used to form any therapeutic or rehabilitative base on which services might be provided.
- Traditional African Education reveals philosophies closely related to present day “western” thinking in special education and Community based rehabilitation, i.e. Participatory learning, community involvement and an emphasis on teaching ‘life’ skills. Perhaps this could be used as a basis for service development?
- Modern education appears to be in a state of disarray, with teachers often on strike, schools often closed and an emphasis on memorization, academic skills and paper achievements.

2.3.0. NATIONAL POLICY ON SPECIAL EDUCATION .

The Federal Republic of Nigeria laid down a National Policy of Education which was originally produced in 1977 and revised in 1988. There are 12 sections in this National Policy and Section 8 is entirely devoted to Special Educational Provision. There are four articles in this section, each article deals with different aspects as described in the box below:

<b>Article 53:</b>	Definition and clarification of the client group - children with disabilities
<b>Article 54:</b>	Definition and clarification of the client group. -gifted children
<b>Article 55:</b>	Purpose and objectives of special education.
<b>Article 56:</b>	Proposed activities and facilities. Parts 1-10.

Each of these articles will be considered in turn.

The state governments follow and interpret the recommendations made in this document according to their own perceptions and budgetary restrictions. It follows, therefore, that although the National policy applies to the entire country, the actual facilities and implementation of these policies varies from State to State. For example Kwara State chose to implement article 56.7 by establishing state schools for the Deaf and Mentally Handicapped, but according to Mba (1991) most other states have so far failed to do this.



### 2.3.1. IMPLEMENTATION OF THE NATIONAL POLICY ON SPECIAL EDUCATION IN OLD OYO STATE, NIGERIA.

#### Articles 53 and 54: Definition and clarification of client group.

**Article 53:**

Special Education is the education of children and adults who have learning difficulty because of different sorts of handicaps: blindness, partial sightedness, deafness, hard of hearing, mental retardation, social maladjustment, physical handicap, etc. due to circumstances of birth, inheritance, social position, mental and physical health pattern, or accident in later life. As a result, a few children and adults are unable to cope with the normal school class organization and methods.

The definition and clarification of the client group are expressed in language and concepts reflecting the state of western knowledge and thinking in the 1950-60s rather than traditional African reflection. This is most probably a direct result of the western education and training of Nigerians during this period, who were probably the authors of this special education policy. The continued use of terminology such as ‘mental retardation’ and ‘hardness of hearing’ shows a lack of movement either towards present day western terminology or towards the development of more appropriate African terminology. Terminology such as ‘unable to cope’, ‘circumstances of birth’ and ‘handicap’, illustrate a vagueness and lack of specific information such as the size of the problem which are more than likely to lead to haphazard implementation with little planning and strategy.

**Article 54:**

There are also the specially gifted children who are intellectually precocious and find themselves insufficiently challenged by the programme of the normal school and who may take to stubbornness and apathy, in resistance to it. Government has already directed that all children, including the gifted as well as those with physical, mental and learning difficulties, must be provided for under the educational system. The corollary of Universal Primary Education, (UPE), therefore, is that special education arrangements must be made for the handicapped and the exceptionally gifted.

Article 54 includes gifted children as a group who also require 'special education'. This provides a different perspective to that common in the UK, for instance. Regrettably, however, the term remains inadequately defined and there is no evidence from the document that the practical implications of this idea have been considered. Instead it serves to create an additional area of need, which has then to be met by already extremely limited resources. It also raises the issue as to whether the personnel within the Special Education Services are in a position to promote appropriate education facilities for gifted children.

The concept of free Universal Primary Education was introduced in Nigeria in 1976 and article 54 reaffirms the inclusion of handicapped children within this frame work. In practice, however, this is a ludicrous denial of the realities of the situation, which place primary education out of the reach of large proportions of "normal" children, due either to inaccessibility or limited finances. Charges are made to cover anything from building development, to books, to subsidizing teacher's government salaries which often go unpaid for months or even years (Akandi 1993). Thus schooling is far from 'free' or universally accessible.

#### **Article 55. Purposes and Objectives of Special Education.**

##### **Article 55:**

The purpose and objectives of special education should be:

- a) to give concrete meaning to the idea of equalizing educational opportunities for all children, their physical, mental, emotional disabilities notwithstanding:
- b) to provide adequate education for all handicapped children and adults in order that they may fully play their roles in the development of the nation:
- c) to provide opportunities for exceptionally gifted children to develop at their own pace in the interest of the nation's economic and technological development.

Article 55 defines the aims and objectives of special education giving emphasis to the role and value of the individual in the development of the nation. There is very little



reference to the concept of individual fulfilment or reaching personal potential but this may be a closer reflection of the cultural values of the country than the more 'western' concepts of rehabilitation and individual independence.

The importance of special educational provision for highly gifted children may be reflected in the emphasis and value attached to University Education in Oyo and Osun State and in fact by all Nigerians. This can be seen by the very ambitious University expansion Programme. In 1970 there were only 6 Universities in the country, but in 1975 the Military Government established seven more. By 1982 there were a total of twenty two, and in 1990 the University of Abuja, the new capital was opened, bringing the total to twenty three. In this way the more gifted members of the states are recognized and catered for but these facilities do not have any direct relationship with the Ministry of Special Education.

#### **Article 56: Proposed activities and facilities.**

Article 56 identifies 10 practical measures for Federal and State Governments to pursue providing concrete suggestions for future activity. This is a welcome departure from much ministerial material which tends to be at a philosophical level and the lack of specificity can be less than helpful. In this section the ten items under article 56 will be discussed separately, in the light of ethnographic research data collection gathered in old Oyo State in 1993. The relevant section of the policy is reproduced in a box at the beginning of each section of discussion for easy reference,

**Article 56: No.1.** The Federal Ministry of Education will set up a Committee to coordinate Special Education activities in collaboration with the Ministries of Health, Social Welfare and Labour.

According to information gathered by interview in 1993 from the Dean of Oyo College of Special Education and several of the senior lecturers, both at the College of Special Education and at the Special Education Department of the University of Ibadan, the



Committee mentioned in this sub-article has been set up, and has met. Details concerning the number of meetings, specific activities or achievements were not available from these sources, so it would seem that if collaboration at ministerial level has been achieved, the information concerning this collaboration has not yet been shared with senior members of staff in Special Education in Oyo State.

**Article 56: No.2.** A census will be taken of all handicapped children and adults by age, by sex, by locality and by type; and schools will be obliged to make yearly returns of children who could be classified as so highly gifted as to attract National attention as to their potential beyond the granting of scholarships to them.

During the situation analysis and from previous involvement with services in Oyo State no evidence came to light concerning surveys except the 1991 population census which is reported to have included questions on disability the details of which are still unpublished. Several attempts including personal visitations, to obtain this information from the office of population and Census in Lagos failed. The latest correspondence (August 1995) from Dr. Alphonse Mac Donald, Country Director for the United Nations Population Fund at the time of the census reports that:

“ The saga of the Nigerian census continues. The data have been cleaned and adjusted and as far as my information goes, the tabulations have all been run. However given the sensitivity of the census in Nigeria, any data release needs to be approved by the President. I understand that since a couple of months, the results are awaiting clearance”

“From our experts, I have had an indication of the quality of data on disabilities. It appears that the data are of mediocre quality, and that there were quite some incomplete data. This is hardly surprising as measurement of disabilities is a very complex issue.”

The Federal Ministry in Lagos undertook a survey of Special Educational Establishments in 1986. From this can be seen that in Old Oyo State, (now Oyo and Osun) there were 29 establishments catering for the needs of “the handicapped”, handling a total of 1,640 pupils.



In 1986 the Federal Ministry of Education estimated a national population of 94 million, 40% of which were children and 10% having some form of ‘handicap’. They used these estimated percentages to create the comparisons made in Table 13, which shows the very low coverage levels of special educational provision achieved in 1983 and compares it with the even lower levels in Nigeria in 1986. This is again compared with the information gathered during this situation analysis in 1993 for Old Oyo State. There would seem to be evidence that services have increased.

**Table 13. The number of School Age Children receiving Education in 1983 (UNESCO Guide to Teacher Training Programmes in Special Education in Africa.) Compared to Nigerian figures of 1986 from the Federal Ministry of Nigeria and information collected in Old Oyo State in 1993.**

	Population in (000)	School Age Children in (000)	Handicapped Children 10%	Handicapped Children rec. Education	% of Handicapped in school
Nigeria '86	94558	37823	3,782,300	9813	0.3%
Kenya '83	16402	6561	656,100	5215	0.8%
Uganda '83	13201	5280	528,000	600	0.1%
Zambia '83	5645	2258	225,800	1400	0.6%
Old Oyo State 1993	5700	2280	228,000	1640	0.7%

A Directory of Institutions for the Rehabilitation of the Handicapped in Nigeria published by the Federal Ministry of Social Development youth Sports and Culture in Lagos in 1981 lists 15 establishments in Oyo State, some of which are not referred to in the Special Education document but which to my knowledge still exist, demonstrating that neither list is complete, and that, although some of the establishments mentioned no longer exist, it is likely that there are even more places in existence than there is information about.

In the process of searching for data on this subject an additional survey came to light and in the absence of information from Oyo State it was felt justified to report it here.

One of the Primary tasks of the new Special Education Department at Jos University, Plateau State, in 1977 was to carry out a comprehensive survey of “handicapping conditions” in Plateau State. It was the first and only survey of its kind in Nigeria. According to Saunders (1984), out of a sample of 6,000 children, 85 “suffered from a handicap” (a prevalence rate of 1.4%) and much lower than the WHO estimates of 10% (WHO 1981) and the UNESCO ones used in the Nigerian Federal Survey (1986) or even Helander’s revised prevalence rates of 5-7% (Helander 1993) Some of the possible reasons for this discrepancy have already been explored in chapter 1 and will not be repeated here, but if a prevalence rate of 1.4% were used on the data from the 1986 Federal survey a higher coverage level of 1.8% can be calculated. This is illustrated in Table 14.

**Table 14** Illustrating the coverage level if the prevalence rate is 1.4% as indicated by the Jos study Saunders (1984 )

Population	School age children (40%)	Prevalence of disability at 1.4%	No. of children in school	% coverage level
94,558,000	37,823,000	529,522	9813	1.8%

**Article 56: No.3.** Government, realizing the importance of a highly trained and efficient personnel in the area of Special Education has already made a provision for the establishment of a National teachers College of Special Education under the present plan. This College when fully established will train teachers and the supportive staff required by schools, colleges, clinics and centres. In the meantime, Government has provided scholarships for those personnel who are being trained at Ibadan University or in Institutions outside Nigeria.

Two of the four centres for Training Special Education Teachers in the country are situated in Oyo State: the Federal College of Education (Special) at Oyo Town and the Department of Special Education at Ibadan University. The other two Centres are located in the north of the country at the University of Jos where special education was introduced from the



very beginnings of the University itself (1976) and Kaduna Polytechnic which started a course in 1973 for social workers with the blind. This eventually led to the development of a Department of Special and Rehabilitative Education where teachers and social workers can now train.

The Federal College of Special Education was first established in 1977 as the Federal Advanced Teachers College. Table 15 illustrates its rapid growth over the last three decades.

**Table 15. Development of the Federal College of Special Education, Oyo, over the past three decades.**

Year	Departments	Students	Staff
1977	5	55	15
1987	5	900	37
1993	10	1,937	80

It can be seen that the number of pupils staff and departments have increased significantly. Within the School of Special Education there is a Department of education of the hearing impaired, (including Audiology and Speech Pathology input) of the visually handicapped, of the gifted and talented, of the learning disabled, of the mentally retarded and of rehabilitative services.

The academic programmes are planned by the Academic Board and are based on the guidelines of the National Commission for Colleges of Education. Students are required to pursue two areas of study and this leads to an award of the Nigerian Certificate of Education (NCE) The entry is through Matriculation and JAMB (Joint Academic and Registration Board). All students study one area of Special Education and another subject area. Qualification on leaving counts as the equivalent of 2 ‘A’ levels subjects.

The first set of students graduated with NCE in 1980 to date the College has graduated 1883 Special Educators at NCE level, some have found employment as administrative officers, principals of special schools or teachers in normal schools. Unfortunately there is no survey to show where all the ex-students of the Federal College are working.

There is a recent initiative supported by UNICEF in conjunction with Birmingham University to upgrade the qualifications of the College Staff. A number of staff are involved in this programme and on completion they will receive Masters Degrees from Birmingham University.

The present accommodation of the college is very limited, especially when catering for such large numbers, but it is due to move to a new site in the near future. Day to day running of the College suffers from many of the problems found all over Nigeria, and lectures are affected by strikes of both the staff and the students. The latter often strike because of living conditions and sometimes because of lecture conditions. The core lectures at the time of my visit were conducted in an open hall with 600 students in the class! The loudspeaker system was broken, so only the students near the front could hear the speaker. Three weeks of the semester had been lost due to student rag week and two weeks of half the staff being away on educational visits as part of their updating process. No planned cover was supplied.

The Department of Special Education at the University of Ibadan currently offers programmes at the Bachelor, Master and Ph.D level in all the main areas of disability. The certificates and diplomas have been phased out and taken over by Oyo College. Between 1974 and 1985 the department produced more than 500 teachers Mba (1991) and increased student numbers would indicate that possibly over twice that number have qualified up to date, although no official figures seem to be available.



**Article 56: No.4.** As soon as feasible, all teacher training Colleges will provide general and basic courses to all perspective teachers who will teach in normal schools but who require such knowledge to identify and help handicapped children In addition the Ministry of Education will arrange crash courses of in-service training for all teachers of handicapped children.

Mba, (1991) reports that this policy has now been implemented throughout the country. Inquiries made at a number of schools in the Ibadan area failed to substantiate this claim. No reliable information was gathered concerning the quantity or quality of this in practical terms.

**Article 56: No. 5.** Government has decided that integration is the most realistic form of special education since handicapped children are eventually expected to live in society. Therefore it has already accepted that special classes and units will be provided in the ordinary schools under the Universal Education Scheme. This will be well staffed and equipped. However special schools where necessary, will be established for the handicapped, retarded and other disabled children.

According to Mba, (1991) in some states integration systems have been initiated as far back as 1980, for example in Imo and Kaduna state, but no information could be found indicating how successful this had been. In Oyo and Osun States there are no government sponsored integration programmes, but Mba (1991) says that there is a special class of pupils with learning problems at the University of Ibadan, Staff School, and this programme has been in existence since the school first opened in 1965.

The researcher's experience of visiting schools in the Ibadan area while supervising teaching practice and assessing children with communication disorders during 1981-1986, failed to identify any evidence of organized integration. There were, however, many children attending those schools, who appeared to need special educational help. Although it is impossible to say to what extent these children's needs were met, they were integrated to some extent into the regular school programme. Casual observation indicated that they were often disruptive or ignored and tended to stay in schooling for a shorter period



Integration in normal schools has yet to be established in practice in Oyo and Osun States, money for staffing and equipping such an enterprise has not been significantly forthcoming. As to whether the concept of inclusion, as outlined in the Salamanca report of UNESCO (1994), as distinct from integration, has made any impact on services in Oyo and Osun State today, it is difficult to say. Given the very desperate state of the country's politics and the effect this has on daily functioning of schools in general, it would seem unlikely.

However on looking through the Federal Ministry statistics publication of 1986 it can be seen that in Oyo State, of the 29 special education centres listed, 13 of them are units attached to some form of bigger institution, whether it be a hospital or school. Some of these units are certainly run as separate entities, but others make efforts at integration in the form of communal sports activities, and joint teaching of the more able children. So it seems that in this way, integration is taking place.

Global criteria, at 5% prevalence rate, suggest that there are probably about 3 million disabled people in Nigeria, 1.2 million (i.e. 40%) of these will be primary school children and according to the International Human Suffering Index, UN Population Crisis Committee (1992) the average number of years spent in school in Nigeria is 1.7. It would seem totally impractical to suggest that the needs of this vast number of 'handicapped' children can be met within the ordinary primary school system, in the foreseeable future.

The financial implications of integrated education are considerable. The Federal Government reports in the press, (Guardian 1993) that grants are being made annually to the States for Special Education. However the States claim that no direct grants are made specifically for special education, and as they use their discretion for administering the funds, most special education programmes have to obtain additional resources from philanthropists and voluntary organizations. Adesina and Igbokwe, (1989) refer to complaints made by special schools to the Federal Ministry that State Governments are not releasing the



funds which should be allocated to them. They call for the Federal Ministry to provide the necessary machinery for accountability.

Ogbue (1975) reports a survey by the Federal Ministry of Education which found facilities catering for the visually 'handicapped', the hearing 'impaired', the physically 'disabled' in the form of pre-school training, primary education in boarding and day schools, integrated programmes, special classes in ordinary schools and hospital schools. Most of these schools at the time of the survey were managed and financed by voluntary agencies, sometimes with small grants from the Federal and State Government departments. Only one school at that time could claim to be state owned and managed.

**Article 56: No. 6.** The Ministries of Education will in consultation with the appropriate bodies, provide special programmes for gifted children, but within the normal educational set up.

The Ogbue survey (1975) makes no mention of a single programme specifically designed for gifted children and certainly there are no special programmes for the gifted in Oyo and Osun States. On a National basis a special centre was set up in Suleja near the new Federal capital. This is the only special programme of its kind known by the Special Education Department at the University of Ibadan.

**Article 56: No.7.** The education of handicapped and gifted children will be free at all levels, up to the University level where possible.

Free education of all children in Nigeria was introduced in 1976 with the Universal Primary Education Scheme however, in practice, charges are made for books, building funds, food, transport and numerous other things. In effect this excludes a large proportion of the population who are not able to meet these expenses. The problems exists for disabled children too, and parents find that they have to find funds if they are to arrange education or care for their disabled child.

The contribution from the State and Local Governments are usually in the form of training and payment of teachers, involvement in the management of the school or centre and ownership of the buildings or land. Budgets do not generally allow for funds to cover maintenance of buildings, books and other educational resources, and usually students are required to bring their own paper and pencils.

Strikes over lack of pay result in long periods of school closure and are often on a National basis. For example there were no schools open in the Old Oyo State between August 1992 and February 1993. Additionally, at times of elections and population census, schools are often used as administration centres and can also be closed to pupils at these times. In the opinion of local teachers known to the researcher in Ibadan, schools in the area have probably been functioning for, at a generous estimate, half of the time during the last four years (1991-1995).

Nigeria's 1993 annual budget for public service expenditure stands at N53.7 billion, N7.999 billion of which has been allocated to education (14.89%). This is an encouraging trend towards helping the situation and an improvement on last years budget which only allocated N.2.393 billion. This improvement seems to have been achieved by a considerable reduction of the defense budget. However, to put these figures into perspective it must be realized that the petroleum subsidy which allows the Nigerians to buy the cheapest fuel in the world, is estimated to cost the nation N 63 billion, annually, close to eight times the total annual education budget.

A certain percentage of disabled students are admitted to further education, the exact proportion appears to be unknown, but in a class of 600 special education students at Oyo Federal College of Education, 16 students were either deaf, blind, or physically disabled. This represents 2.6% of the class.



**Article 56: No.8.** Vocational Schools will be made to reserve places for further education of handicapped children and adults. Other multi-purpose vocational schools will be established as needs arise. Government will provide suitable employment for handicapped workers, and the ministry of Social Development, Youth and Sports will be requested to examine the possibilities of establishing sheltered workshops for those handicapped who after training cannot bid on equal terms with others for recruitment into commerce and industry. The committee on special education and National Council for the Rehabilitation of the disabled will be fully involved in these plans.

According to Mba (1991) there are no State Vocational Rehabilitation Centres or sheltered workshops in old Oyo State, but many of the educational establishments have vocational aspects to their curriculum. The Rehabilitation Centre at Monyia does have input from the Federal Ministry of social services, but does not come directly under the local government. The centre caters for 60 pupils who are meant to be over 16, and stay for one year only. They can receive training in block-making, typing, weaving and dyeing, shoe making, animal husbandry and home economics. There are 25 staff at the Centre, 10 of whom are disabled themselves. The initiative for this centre comes from disabled people. In practice there are many problems, for although the salaries of the staff are paid for by the state government through the ministry of social services, the costs for running the centre have to be met by donations and other money. There is a charge of N1,008 per year, (exchange rate in 1993 N43 to £1) to the trainees towards food and accommodation, but materials for training have to be paid for through donations. Reports from other quarters say that often young children are admitted who should be in school, and that the 60 trainees do not appear to move on after one year at the centre as is intended.

Theoretically, 2% of places in technical colleges should be reserved for disabled people. According to staff at the special education department of Ibadan University only one technical college in Oyo State comes close to meeting this requirement, where a number of deaf students are known to get placements.



There is a community based vocational rehabilitation programme situated in Ibadan established by the Federal Ministry of Culture and Social Welfare, in collaboration with The International Labour Organization (ILO) and the United Nations Development Programme (UNDP). This programme has been set up to offer support nationally to vocational rehabilitation centres and there are technical centres in Lagos, Sokoto, Kano, Enugu and Oshodi. The project is also assisting Oyo State Government to start a community based vocational rehabilitation programme in the Ibadan municipal government area. The aim is to train disabled individuals locally in skills which are relevant and marketable within the community. Disabled people are ‘apprenticed’ to a local artisan for 6 months, after which they are assisted in setting themselves up independently. So far there have been two groups of 20 trainees, but it seems there are problems in achieving the necessary level of skill in this short time span.

**Article 56: No.9.** Children’s clinics will be attached to most hospitals for the early identification of handicapped children and for curative measures and medical care before and after they reach the age for primary schooling.

It is difficult to know what kind of ‘clinics’ this part of the policy refers to, as educationally funded services attached to hospitals, would be somewhat unusual. However, one such establishment in Oyo State is listed in the 1986 statistics, that is the Special Education Unit at the State Hospital in Ibadan. The services offered are predominately occupational therapy, and the service is funded by the Ministry of Education.

A Speech and Hearing Clinic can be found in the Special Education Department of the University of Ibadan. This was originally fully equipped with audiometers, Tympanometry, Brain Stem EVR, sound proof booths and adequate toys and play material for children. This clinic ceased to function in the mid 1980’s, the equipment is mainly broken down and staff with adequate clinical skills are not available. Thus the clinical input into the Speech Pathology and Audiology courses run at the University since 1983 is negligible. It is reported by the staff of the department that the occasional client is still seen, but there



were no figures on client numbers available when inquiries were made in 1993 . The last figures obtainable were for 1982 during which 111 patients were seen.

Child welfare clinics exist in most areas of the State, but attendance is spasmodic. The people are generally unreceptive to preventative medicine, and attending a clinic with a child when all is well is not easy for them to understand. Additionally, local clinics tend to be understaffed with poor facilities, they are not likely to have water or reliable electricity, and the staff often have very little or no training in Primary Health Care. As we have seen from previous sections , there are few facilities for disabled children so even when these children are identified, there is often very little help available for them.

Children’s clinics are part of the outpatients service in two hospital Centres in Ibadan, Ring Road State Hospital and University College Hospital. There are paediatric clinics in both hospitals, and ENT at University College Hospital (UCH). There are also physiotherapy, occupational therapy and speech therapy services at UCH. However for paediatric services there are no pre-school rehabilitation services so often management and medical assistance is all that can be offered following identification. Orthopaedic and plastic surgery facilities exist in both hospitals.

**Article 56: No.10.** Ministries of Health, Education, Social Welfare, Social Development and Labour will work jointly on most programmes for handicapped children, and the National Council on Special Education will be composed to reflect this collective responsibility.

Evidence of collaboration between the Ministries is difficult to find except at a conference level. The joint initiative for the community based vocational rehabilitation programme has involvement from all the Ministries with UNDP/ILO and was the only practical evidence of collaboration that could be identified during this situation analysis.

### **2.3.2. IMPLICATIONS FROM INFORMATION GATHERED ABOUT SPECIAL EDUCATION ON SERVICES FOR PEOPLE WITH COMMUNICATION DISORDERS.**

- \*\* There seems to be evidence of poor communication and coordination between the ministry of Education and the senior personnel working in the field.**
- \*\* Coverage levels of present service are very low, even using low prevalence levels collected from locally based data.**
- \*\* It is important to note the educational structure set up within Special Education. This is relevant for future training needs and the point of entry within the system.**
- \*\* There has been considerable development of services over the past decade but little evidence of evaluation or monitoring.**
- \*\* There have been problems with implementation but within the field of Special Education there have been many successes too. This has mainly been due to the few very dedicated and knowledgeable people, many of whom are disabled themselves who have continued to fight and work hard for the goals they had identified.**
- \*\* The perception that the needs of gifted children are part of 'special education' provision have created additional problems.**
- \*\* Disabled people themselves have played a leading role in the development of Special Education services and hold positions as teachers, lecturers, managers and students at University.**



#### 2.4.0. NATIONAL POLICY ON PUBLIC HEALTH CARE.

The health services of Nigeria have evolved through a series of historical developments including a succession of policies and plans which have been introduced by successive administrations originating from the British Army Medical services. In 1987-1988 Ransome-Kuti, the then Minister of Health, developed a new health policy as part of the fourth national development plan. Ransome-Kuti et al (1989) saw health development as an essential component of National Philosophy and aimed to formulate a policy in the context of national goals and philosophy. It is this policy which will now be considered in relation to services in Oyo and Osun States relating to people with communication disorders. A copy of this policy can be found in Appendix 1.

#### 2.4.1. HISTORY

The public health services in Nigeria originated from the British Army Medical Services which were gradually extended to cover local civil servants, their relatives and eventually the local population living close to the government stations. The first attempt at planning ahead for the development of national health services in Nigeria, took place in 1946 after the second world war and when the country became independent in 1960, health policies were enunciated in various forms, 'training of doctors' or 'development of hospitals', all had an emphasis on cure, rather than prevention. The implementation of these policies seems to have lacked management, evaluation and accountability. Ityavar (1989) says that:

"each plan recognizes the short fall of the previous plans but nothing is done about it." p 293

According to Ityavyar (1989) problems arising from this policy are more related to implementation and accountability than to content. He says that:

"The health policies of Nigeria and the role of the State in health have not substantially changed in spite of the various reforms and development plans. Social inequalities in health are in fact growing.... Disregard to certain groups of Nigerians becomes even more apparent when the politics of health funding are discussed." p294

2.4.2. BUDGET IMPLICATIONS

The three levels of government in Nigeria (federal, state and local) share the responsibility for the financing of different health services can be seen in the Table 16.

Table 16. Areas of financial responsibility.

Federal Government	Teaching, Specialist establishments, Training Health Personnel such as physicians, funds for research, control of communicable diseases, environmental and occupational health.
State Government	Regional Hospitals and Health Centres Running costs of private Hospitals especially NGOs.
Local Government	Primary Health Services

Though the Federal Government provides general direction for health policy each State can interpret it as it pleases, for example in the Shagari regime Oyo State was one State that chose to provide free health services while others preferred to use the very limited resources for other things. The percentage of the national budget directed towards health care is very small, see Table 17.

Table 17. Percentage of National Budget directed at Health Care taken from the text of Ityavyar (1989) and The Guardian Newspaper (1993)

	% of annual state expenditure on health	% of annual State expenditure on Education.
1960 - 1966	4%	
1969	1%	
1974	1.4%	6.4%
1975 - 1985	1-2%	
1979 - 1983	3%	
1984	1.8%	
1985	1.9%	
1993	5%	14.98%



The percentage of the budget allocated for health immediately post-independence compares with the 1993 allocations, a serious dip occurring during the civil war when most of the funds were directed to defense and security. In the 1993 Budget N2,685 was allocated to the development and maintenance of health care services and according to statements in The Guardian News Paper (1993), the majority of this in Oyo State is to be spent on maintaining hospital facilities already established. It can be seen that this sum represents 5% of the public service Budget in contrast with the 14.89% spent on Education. However when considering the total budget it only represents 2.23%, as 58% of the budget is used to furnish the National Debt. This financial commitment, although on the increase does not give practical support to the statements made in the policy and provides scant financial backing for the management and coordination implications of the local, State and Federal government departments working together and evaluating outcomes.

#### **2.4.3. EVALUATION, MANAGEMENT AND INFORMATION GATHERING.**

Ransome - Kuti et al (1989), laments that it is not possible to make accurate statements about the health status of Nigerians mainly because there is no reliable system for collecting basic health statistics. He says that the limited health statistics available (Nigerian Fertility Survey 1981-82) indicate the general poor health of the nation with a child mortality rate of 144 per 1000, Infant mortality rate of 85 per 1000. and a life expectancy level of 50. Ransome-Kuti says that most of the deaths and serious illnesses in Nigeria are due to conditions that are easily preventable such as diseases associated with inadequate environmental sanitation and poor personal hygiene which are often compounded by malnutrition.

More recent data gathered from the indicators developed by the UN agencies supports these observations as can be seen in the following tables.

**Table 18a. and 18b. Information concerning Nigeria, Uganda and South Africa relevant to Health Policy and Planning from the Human suffering Index (1992) and The Third World Guide, Instituto del Tercer Mundo (1994)**

**Table 18a.**

Place	Position on Human Suff. Index	Life Expectancy	Access to clean water	Infant Mortality	One Physician for every
Nigeria	70/93	48 years	48%	170/1000	7,540
Uganda	85/93	49 years	20 %	167/1000	22,291
South Africa	61/93	64 years	95%	91/1000	1,880

**Table 18b.**

Place	Total Pop	Urban pop	Rural pop	Literacy	GNP/capital per year	External debt
Nigeria	109 m.	35 %	65 %	M-62%	250\$	32.8 billion
Uganda	18.4 m.	10%	90%	M62% F-35%	260\$	1.8 billion 98\$ pc
S. Africa	34.5 m.	59%	41%	M-78% F- 75%	2,470\$	Not reported

Nigeria is higher on the Human Suffering Index than would be expected when one considers its oil wealth and long history of education and development. The Nigerian figures show a general deterioration from those of 1982, indicating a decline in the health status of Nigerians over the past decade. Of its estimated 109 million people, the majority live in rural areas yet medical services and facilities are still urban based. The literacy level for women is low, with a Gross National Product per capita of less than the Gross National Debt per capita. Uganda and Nigeria have a similar life expectancy, infant mortality, literacy levels and GNP, in spite of a highly significant difference between the number of physicians per capita, a much lower percentage of people with access to clean water in



Uganda and a different rural / urban population spread. South Africa, with a much lower position on the human suffering index would probably be lower still, if its political background were ignored. It shows better results in all areas, with a significantly higher GNP, some of which must be reflected in health and education services for all, with 95% of the population having access to clean water and higher literacy levels for both men and women.

Ransome-Kuti et al (1989) feels that health services in Nigeria show major defects involving:

- inadequate coverage, (no more than 35% of the population has access to modern health care services).
- disproportionately high investment in curative services to the detriment of preventative services,
- poor coordination and management of the agencies involved.
- minimal community involvement ,
- lack of statistics and information,
- financial resource allocation inadequate.
- the basic infra-structure and logistic supports are often defective because of inadequate maintenance unreliable water and electricity supplies, and poor management. Federal Ministry of Health (1988.)

The second article of the health policy, see appendix 1, reflects a recognition by the Ministry of Health and the Policy makers, of the grossly inadequate health care service which is at present offered to its people. Such recognition should hopefully be the first step in any move towards change.

#### 2.4.4. SERVICES

Within the State system services have developed in three tiers and can be related broadly to the financial structures described in the previous section:

**PRIMARY HEALTH SERVICES** are closest to the people and the responsibility of local government. Problems with the implementation of this scheme included the development of basic health units in each state. According to Ransome-Kuti et al (1989) after an expenditure of about N200 million at the end of 1983 (approximate exchange rate at that time N1 = £1) most of the facilities remained uncompleted all over the country. He felt that during the implementation of the scheme the principles of Primary Health Care (PHC) were not applied. The community did not in any way participate and at the end of the planned period and its extension till 1985, no PHC existed anywhere in the country.

**SECONDARY HEALTH SERVICES** are for those problems that cannot be solved at the Primary Health Care level and are delivered in general and district hospitals under supervision of the State government. They provide specialized services to patients referred from the primary health care level through outpatient and inpatient services of hospitals for general medical, surgical, paediatric patients and community health services. They also serve as administrative headquarters, supervising health care activities to the peripheral units. The Health Policy states that secondary health care should be available at the district, division and zonal levels of the state. Adequate support services such as laboratory, diagnostic, blood bank, rehabilitation and physiotherapy should be provided.

**TERTIARY HEALTH SERVICES** in teaching and specialist hospitals supervised by the Federal Ministry of Health. This type of care consists of highly specialized services provided by teaching hospitals and other specialized establishments. In the states of Oyo and Osun, there are two large training Hospitals, University College Hospital, Ibadan, and Obafemi Awolowo Teaching Hospital, Ife, which between them have a total of 1,000 beds. There



are also two large State Hospitals, one in Ife and one in Ibadan. All these four hospitals purport to having a full range of specialities, including ENT, Orthopaedic, Psychiatric, Paediatric and Neurological. In practice however services in these areas are somewhat unpredictable, and may not exist for years at a time, while staff are away on training programmes or sabbatical leave, or when equipment is broken or medicines are in short supply. In 1993 there had not been any ENT operations for over a year due to the shortage of medicines and functioning equipment, (personal communication from the ENT Consultant. 1993)

Additionally the States in question, have two other quite large missionary Hospitals, Ololowo Catholic Hospital, in Ibadan, and the Baptist Mission Hospital in Ogbomoso. There is also the Wesley Guild Hospital in Ilesha which has recently become attached to the teaching hospital in Ife. With two of the longest established training establishments in the country located in the area, it might be that the medical services offered are more comprehensive than in any other area of Nigeria.

Only one of these centres, University College Hospital, offers free medical services and medicines, and interestingly these services are reported by its staff members to be underutilized. Attah (1986) comments on the under utilization of public sector health facilities in Imo State, Nigeria, and lists the following possible reasons:

- **Limited Access.** Many people simply live too far away and with no public transport and limited funds they are excluded from such services.
- **Prohibitive costs** in terms of time and money. Since 1985 registration deposits have been demanded before treatment and one night in the hospital is calculated to be the equivalent of a month's salary for an average worker.
- **Lack of supplies and equipment.** It is common practice to send the patient's family out to buy the drugs needed as they are not usually available in the hospital.
- **Poor attitudes of the health care workers.** There is a wide spread perception of an uncaring attitude and doctors caring more about "purse than pulse"

- **Nepotism** is often demonstrated by the need to ‘know someone’ before it is possible to obtain care.
- **Diversion of services and supplies often to the private sector** by referral to private clinics and the sale of drugs to market traders.
- **Unofficial surcharges.**

Attah (1986) feels that the high cost of health care drives people to the traditional health practitioners and people only contact a western trained doctor as a last resort. Personal experience in Oyo State would corroborate these observations. The researcher has often observed empty wards and outpatient clinics, excessive charges made for services which should be provided free, the need to ‘know someone’ before cooperation or services are made available. The tremendous distances travelled by patients for treatment and a lack of drugs and supplies.

A speech therapy service exists at the tertiary level of service in Oyo State and by special request the therapist provided a breakdown of the type of clients seen. Although statistics are requested each year, the directive is never enforced or made public. Her duties were clinical and predominantly audiological, yet she was specifically employed as a Speech Therapist. The Audiologist had left for Saudi Arabia the previous year and she had taken over most of his duties. He had not been replaced.

In a two month period in 1992 this speech therapist had seen a total of 50 patients, 38 for audiograms and the remainder diagnosed as following:

Stammer	1
Hearing Impairment	10
Aphasic	1
Language delay	2
Articulation disorder	2
Laryngectomy	2



Some of these cases had been seen several times but she had no record of how many times she had seen each patient. She felt her time was underutilized.

## **PRIVATE MEDICINE**

Non government agencies, private practitioners and company provision, provide extensive services in all areas of care and help to meet the health needs of the more elite members of the Nation. In Oyo and Osun State there are numerous private clinics and hospitals. Although these establishments are supposed to be registered the researcher was unable to obtain any kind of list. Local knowledge of the clinic's whereabouts, reputation and performance seemed to be communicated by word of mouth. There seemed to be no structure for accountability.

## **TRADITIONAL MEDICAL CARE.**

Many people, particularly in the rural areas, use native medicine. Bone setters seem to have a good reputation and according to local Nigerians known to the researcher, herbalists would offer cures for the deaf and mentally handicapped or disturbed. (There seems to be a tendency not to distinguish between the latter two by the informants.)

## **COMMUNITY BASED REHABILITATION.**

The only community based rehabilitation service that the researcher could find evidence of in Old Oyo State was the community based vocational rehabilitation project in Bodija, Ibadan. This is jointly funded by the Federal Ministry of Culture and Social Welfare, The International Labour Organization (ILO) and the United Nations Development Programme (UNDP). It is a new development and has only been in existence for just over a year. Details of this project have already been described in section 2.3.1. under article 56 No. 8 of the Special Education Policy.

#### **2.4.5. IMPLICATIONS FROM INFORMATION GATHERED ABOUT HEALTH CARE FOR THE DEVELOPMENT OF SERVICES FOR PEOPLE WITH COMMUNICATION DISABILITIES.**

- Poor coverage levels in nationally run health services. Services seem to be better developed in the private sector.
- Implementation of a PHC system is poor with indications that funds have been diverted away from the original goals.
- Poor levels of accountability and evaluation.
- Lack of reliable information and statistics for use in planning decisions.
- Financial commitment of the government would seem small in relation to the overall budget and the health needs of the people.
- A large proportion of the finances available seem to be directed towards curative care.
- There is evidence of poor coordination and management with particular difficulty between the Federal, State and Local Governments.
- CBR has only just started in Old Oyo State.
- There would seem to be a very extensive traditional medical health care service about which a limited amount of information is available.



### **2.5.0. NATIONAL POLICY ON SOCIAL SERVICES.**

Unfortunately the researcher was unable to obtain a copy of the social development policy in Nigeria in spite of visits and letters to the Ministry of Social services and contact with Social workers in Ibadan, The Director of Social Service in Ibadan and the Director of the Rehabilitation Centre in Moniya. All those contacted did not have a copy of the policy but said that they could obtain it for me. This was not forth coming. They reported that Oyo and Osun State did not have a separate policy, but followed the guidelines set out by the Federal Ministry of Social Development, Youth and Sports.

#### **2.5.1. IMPLEMENTATION OF THIS POLICY IN OYO AND OSUN STATE.**

Without knowledge of the policy it is difficult to comment on its implementation. However it was decided that some value may be gained from a description of the local services supported by the Social Welfare Department.

The Ministry of Social Development, Youth and Sports in Oyo State, like its counterparts in other states, is divided into three departments. Each department has its own Director.

- The Social Welfare Department deals with disabled people, delinquents, marital disputes, abandonment, adult welfare and support of voluntary organizations.
- The Community Development Department deals with all group work, self help work, women's groups etc.
- Youth Affairs deals with all the youth programmes and sports development.

**STAFFING.** The number of Staff employed in the whole Ministry in the Old Oyo State area is reported to be around 2,000. However the number employed in the Social Welfare Department is 540, about 400 of which are Social Workers.

**THE SERVICES** offered by these social workers fall into five categories.

- Counselling people who are disabled and directing them to services.
- Assisting disabled people to get employment.
- Assisting them to get a loan from the State Government.

-After care service.

- Input, mainly at managerial level, into all the Associations and Voluntary bodies dealing with the disabled. All Voluntary bodies have to register with the Community Chest Council, Oyo State Government give the council a grant (N150,000 annually) and the Community Chest Council supervises its distribution.

Only one social service establishment is run totally by the State in Oyo and that is the Ibadan Remand Home. This has two sections to it, one that deals with young offenders, about 100 children at any given time and a child care unit for abandoned children, a number of whom are disabled in some way.

The Social Welfare Department also gives support by way of a state grant to five other establishments throughout the State.

1. There are 6 Rehabilitation Centres in the whole of Nigeria which have been established by the Federal Government. There is one in Oyo State at Moniya, and, although it is federally funded, the State contributes by providing the salaries for the staff, and food for the Trainees.

2. Oluyole Cheshire Home School, Ibadan . Founded in 1959 cares for about 30 handicapped children, and attempts to make them useful citizens. They have children with polio, hearing impairment, visual impairment and cognitive impairment.

3. Ibadan School for the Deaf, Founded in 1963, has approximately 250 pupils and aims to educate the deaf academically and vocationally.

4. School for Handicapped Children, Ibadan, established in 1964, takes all categories of disability and has about 30 trainees. It aims to give educational and vocational training.

5. The Nigerian Training Centre for the Blind, Ogbomoso, established in 1958, gives educational and vocational training to about 50 trainees.



Each of the establishments receives a state grant with staff provision of social workers where appropriate. All of these establishments are within the boundary of new Oyo State leaving Osun State totally without facilities of this kind. In practice however the people of Osun state have access to these facilities as they have always done.

**THE MEDICAL SOCIAL WORKERS** work separately from the social workers within social services and 13 are to be found at University College Hospital. Their jobs are entirely Hospital based and the majority of their work involves assisting people with financial payment of hospital fees. They also work with disabled people and their families, run a hostel for relatives of patients to stay in, offer marriage guidance counselling and spend quite a lot of time fund raising to do their work. Although their salaries are paid, offices cleaned and staffed, telephones and electricity supplied, they get no other running costs from the state.

#### **2.6.0. VOLUNTARY SECTOR.**

The Voluntary sector has been responsible over the years for the establishment of a great many of the facilities for disabled people, and their present day contribution is still considerable. Philanthropists, missionaries and churches are often responsible for initiating and running services which are too numerous to mention. Associations of people with a common interest often develop, but when key figures move away or die, the activity of the association may cease. Some survive, in spite of the changes, and three such organizations are described below.

##### **2.6.1. NIGERIAN SOCIETY FOR THE HANDICAPPED.**

The Nigerian Society for the Handicapped was established in 1975, and has branches in some states but not in others. I was unable to trace any of its activities in old Oyo State, but it seems active in Kwara State for example. The purpose of the society is to act in an advisory capacity to the Government and any other interested parties on matters affecting the care, education and treatment of handicapped children, to publicize their needs and



to arrange lectures, conferences and seminars to promote knowledge and understanding of handicapping conditions. They have been responsible for providing sponsorship, buying hearing aids, financing people to attend overseas conferences, and in Kwara State building a Vocational Training Centre for disabled people.

### **2.6.2. NIGERIAN NATIONAL ASSOCIATION OF THE DEAF. (NNAD)**

This National Association was established in 1986 and has branches in most states of the country including old Oyo State. The membership is open to any hearing impaired national of Nigeria of 18 years and over. Honorary membership can be conferred on hearing individuals who have either given appreciable service to the deaf community or who hold high positions of influence and respect. In practice the membership is mainly deaf individuals. The purpose of the Association is to mediate, on behalf of its members, with Federal and State Government for employment and the general welfare of deaf people. It convenes conferences, promotes the exchange of information and assists in helping the public know more about the problems of deaf people. A recent project has been to negotiate for a regular TV programme which teaches sign language. There are approximately 200 members nationally, a general meeting is held once a year, state branches hold their own meetings locally, but during the last year in Oyo and Osun state there has only been one meeting. There are many difficulties to be faced in effective functioning, most of which relate to cost. They try to raise money but are not very successful. Very few people can afford to attend the meetings. There is also a conflict of purpose, part of the membership would rather the Association be run as a social club. The work of the Association falls on very few shoulders and it would seem difficult to maintain the impetus.

The Association is aware of many social clubs for the Deaf in the States of Oyo and Osun, however they do not appear to be easily sustainable, no list of such organizations exist. They are often set up by hearing people and deaf people are very sceptical of societies run by hearing people, as they do not have control and cannot say how the money should be spent. According to a deaf university lecturer, even the work done by the Nigerian Education Research and Development Council (NERDC), is looked upon with scepticism by many educated deaf people, as they see it as an organization more involved with its own status than with the care or welfare of the deaf.



### **2.6.3. NIGERIAN EDUCATIONAL RESEARCH AND DEVELOPMENT COUNCIL.**

The NERDC was established in 1972 as a body of professional people drawn from Federal and State Ministries of Education, Universities, Schools, Teacher Training Colleges and the Nigerian Institute of Social and Economic Research. The council promotes and monitors educational research and has a Special Education Division. This division has organized seminars, workshops and conferences, bringing together administrators and special educators to work on specific schemes. The most recent of these was the introduction of special education courses into all teacher training institutions in Nigeria.

### **2.7.0. TRADITIONAL MEDICAL CARE.**

Given the sensitivity of the issue, the political unrest and extensive strikes which took place during the time of this analysis it became very difficult to gather first hand information about traditional practices. There are a number of studies and articles on this subject and these are reported on in the literature review but it was not possible to verify this information at first hand experience. This was most regrettable as the researcher recognizes the importance of this area and the implications it may have for service delivery.

#### **2.7.1. IMPLICATIONS OF TRADITIONAL KNOWLEDGE IN DEVELOPMENT OF SERVICES FOR PEOPLE WITH COMMUNICATION DISORDERS.**

- A body of people exist at community level who have a core of traditional knowledge, some of which may be useful to people with communication disabilities
- These people are in the community and easily accessible to the people who need help.
- The efficacy of traditional practices are unknown.
- This body of people on the whole are not keen to share their knowledge or accept the views or scrutiny of other disciplines.

### **2.8.0. STATE TRAINING AND PROVISION OF PROFESSIONALS.**

It is not possible to cover in detail all professionals dealing with people with communication disorders. It was decided to look at the training of doctors, speech therapists, audiologists, primary health care workers, physiotherapists and traditional healers, as those professionals most likely to be dealing with people who had communication disorders. Further information about professional organizations in Nigeria can be found in Appendix 2. The training of special education teachers has already been discussed in section 2.3.1.

#### **2.8.1. MEDICAL DOCTORS.**

Many Nigerian Doctors have trained overseas, mainly in UK. and USA, the number of these that return to Nigeria is unknown, but the impression among the medical profession in Nigeria is that a great number of these eminently qualified men and women do not return to work for their country, but take up posts in the country of their training or take up offers of employment where remuneration and working conditions are more favourable, e.g.. USA. UK, Saudi Arabia.

Medical training in Nigeria was established in Oyo State in the early 1960's. University College Hospital, Ibadan was set up by The University College of London, and in its early years the students became graduates of London University. In the late sixties the College of Medicine at University College Hospital became independent, its qualifications were, and still are, recognized in the UK. and the training was reputedly the best in black Africa.

Establishment of Ife University and the Obafemi Awolowo Teaching Hospital followed closely behind in the early 1970's, and both of these Universities have been training doctors ever since. The training from Ife however, is still not recognized internationally. Entry qualifications for this training was, until recently, West African School Certificate and three appropriate 'advanced levels' taking a very UK. based model. Recently however this has been changed and entry is based on School certificate, which is roughly equivalent the UK General Certificate of Education with 5 passes, and then through the Joint Association Matriculation Board, JAMB, which is four subjects including English and Math's



and two other subjects appropriate to the course of study. This exam is taken at the same time as School certificate by all students wishing to pursue further education. Selection for students is based on their score out of 400, for entry into medicine at UCH, 300 is the minimal requirement. Other medical schools, particularly in the north of the country have a much lower cut off point. The training is 5 years in all centres, and at UCH around 60 - 70 doctors qualify each year. The Nigerian Medical Council controls the standards and quality of the Medical Schools.

Technically all doctors should register with the Nigerian Medical Association, however according to Nigerian doctors known to the researcher, this is badly monitored and many do not. The great majority of doctors work in private clinics or hospitals (NB. A large number of these establishments are also run by nurses and may have no qualified doctor in attendance) The NMA are not able to keep an up to date register of practitioners. Although it is felt there must be several thousand doctors in the country, no one is quite sure how many. People with medical training often leave the country for employment elsewhere. Medicine is one of the worst sufferers from 'brain drain'.

### **2.8.2. SPEECH THERAPISTS.**

The Speech Therapists with clinical training and expertise have all trained abroad in either America or Britain. Out of the 50 or so members of the 'Nigerian Speech and Hearing Association' about 10 hold Internationally recognized qualifications.

Training in the theory of Speech Pathology forms part of the Special Education course at the University of Ibadan. As far as the researcher could ascertain, this is the only place where such training exists in the country. Although speech courses are also offered at the Federal Teachers Training College, these students would not be able to take employment as a Speech therapist as they do not have a degree. The courses offered which relate to speech therapy practice are, Audiology and Speech Pathology, Speech Language and Articulation disorders, 'Physiologic Phonetics', Communication skills, Speech and Language disorders in children and Guidance and Counselling. There are also related

courses in psychology, hearing impairment, learning disabilities and mental retardation. There is no clinical aspect to this course. Students who choose to specialize can study speech pathology to a masters and Ph.D. level. The few who do this, tend to stay at the University to teach.

When qualified, practitioners have to learn on the job, so it is hardly surprising to find that their clinical skills are very poor. Quite understandably they become discouraged and often leave for another field of work.

Looking at the members of the Nigerian Speech and Hearing Association whose practice is oriented towards 'speech' rather than 'hearing,' it would seem that they represent a very small proportion, possibly 3 or 4 in the whole country. The tendency is towards professionals holding dual qualifications in these two fields and using their audiological knowledge as a basis for setting up clinical services.

In old Oyo State, the people with the training I describe can be found in the graduate and postgraduate training establishments. Sometimes as part of their duties they are expected to run a speech and hearing clinical service, for example at Oyo Federal College of Education, (2 members) in the Special Education Department of University of Ibadan (3 members ), in the University teaching Hospital (1 member) or in private practice (1 member)

It is quite likely that Oyo State is better served with this kind of professional than any other area of Nigeria. However the number of clients they serve is likely to be very small if the example given in section 2.4.4. is typical.

### **2.8.3. AUDIOLOGISTS.**

The training for Audiologists takes a similar pattern to that of Speech Therapists in that they have either received training abroad or have done the training in the Special Education Department of the University of Ibadan. The courses include, clinical audiometry, principals



and practice, and courses on hearing impairment, auditory training and education of the deaf. The course on clinical Audiology is a practical one, and students on the whole learn how to conduct an audiogram, however due to considerable difficulties with maintenance and repair of equipment the Impedance, Brain Stem EVR, and speech audiometry is rarely presented in more than the theoretical form.

Within the Nigerian Speech and Hearing Association there are a greater number of people practising as Audiologists than Speech pathologists/therapists. In the Ibadan area the speech therapist at UCH does mainly audiological work, and at a private speech and hearing clinic in the town the majority of clients are deaf. Until recently there were two hearing aid services operating in Ibadan town but they have recently moved to Lagos. As far as the researcher could ascertain there are no facilities of this kind in the rest of Oyo and Osun State.

#### **2.8.4. PRIMARY HEALTH CARE WORKERS.**

Primary Health care workers are usually trained nurses who have sometimes attended different short courses on certain aspects of Primary Health Care. These are offered at UCH and the Ring Road State Hospital in Ibadan.

Nurses training is offered at many Hospitals throughout the state, namely UCH, Ring Road Hospital Ibadan, Ogbomosho Mission Hospital, School of Nursing at Oshogbo, Oyo, and Ife. It is a three year training and students need matriculation to enter, (the equivalent of 5 'O' levels.)

The provision of Primary Health Care workers in the states of Oyo and Osun is very limited. There are between 17 and 20 Health Centres in the State, but most of these are poorly equipped and badly staffed.

They aim to provide mainly preventative services, and have vaccination programmes supported by UNICEF, oral rehydration therapy, school services and community services.

They also act as a referral centre to more specialized clinics and provide birth attendants if requested.

Some years ago the funding for these Health Centres came direct from the Federal Government; now this responsibility has been handed over to the State. The Social Democratic Party, which is the ruling party in Oyo State has declared that treatment at Health Centres should be free to those under 18 and over 65 . In practice this is not the case, and payments have to be made for drugs and any other materials.

Centres which used to have a staff of around 25 now find their numbers have been much reduced. This is due not only to the lack of money to pay their salaries but because the staff themselves have become frustrated by working in such poor conditions with very few drugs or other facilities, and have decided to leave and go into the private sector. Only one of the health centres in Oyo State has a doctor; the rest are staffed by nurses only.

There are many private clinics which operate independently of the state but services are still mainly curative. They often specialize in some area of medical service, e.g.. maternity . Their services are obtainable for payment only. They appear to represent a large proportion of the medical services in Oyo State.

The percentage of the population attending the State Health Centres is known to be very low (around 15%). Local people use the services of Traditional Health care usually before going to the clinic, herbalists and bone-setters particularly, are considered to have great skill. People go to the clinic as a last resort. One health care worker I spoke to said that on average they would have about 15 people in the clinic per day.



### 2.8.5. SOCIAL WORKERS.

The Training for Social Workers can vary from a one year course at a staff training centre, with basic school certificate entry, to a Bachelors or Masters degree in social sciences or guidance and counselling. The training seems to vary considerably both in level, content, and practical components. There seems to be some disagreement amongst the professionals I spoke to as to whether the one year practical training is also compulsory for the University graduates.

There is a staff training centre in Ibadan which opened in 1968 and is in fact attached to the ILO /UNDP Community Based Rehabilitation Programme. The one year programme is offered here.

The University of Ibadan offers several programmes that have courses related to some aspect of social work, for example, guidance and counseling, adult education, social sciences etc. A new Masters programme has recently started in social rehabilitation in conjunction with the University of Pennsylvania. They are accepting any degree as an entry requirement but experienced social workers are not eligible unless they have a degree already. The University of Ife also offers courses in rehabilitative studies.

### 2.8.6. PHYSIOTHERAPY.

Physiotherapists can train in Nigeria at four different Universities. University of Lagos, Nigeria, Ife and University College Hospital, Ibadan. The Physiotherapy training in Oyo State is at University College Hospital and was established in 1970. It has an annual quota from the National University Commission of Nigeria for 35 students per annum. The one at the University of Ife in the Department of Medical Rehabilitation was established in the mid 1980's. Both follow a similar entry pattern and curriculum. The courses offered are four year degree courses offering a B.Sc. in Physiotherapy. The entry qualifications are five credits at general certificate of education ordinary level, in Physics, Chemistry, Maths and English Language, plus satisfactory entrance levels at matriculation through the Joint Admissions Matriculation Board. This is a separate examination, and passes in both these

examinations are required. Such students will enter the four year programme, but 'direct entry' is offered to students who have obtained a minimum of GCE advanced levels in two subjects including the subjects physics and Biology. These Students will commence a three year programme. The final two years of training are predominantly practical. Completion of an independent study is also required.

When qualified, Physiotherapists are required to register with their professional body, and their performance will also be monitored by the newly set up Medical Rehabilitation Registration Boards for four paramedical professions, including Speech Therapy. Physiotherapists are paid on a National Paramedical pay scale, and can find work in Federal State and local Hospitals. Some work with sports centres or in private practice.

The Head of the Physiotherapy training Department estimated that there were about 500+ Physiotherapists in the country, 300 of which had been trained in Ibadan. There are about 35 registered with the Oyo and Osun State Branch of the Nigerian Society of Physiotherapists.

#### **2.8.7. TRADITIONAL HEALERS .**

Due to the difficult political circumstances in Nigeria at the time of this situation analysis, it was not possible to gather much first hand information on this subject. However exploration of local data was substantiated by informal inquiries amongst the local residents who observed a need and value for traditional services and expressed a faith and satisfaction in some of the services they provided.

Attah (1986) describes traditional healers are people trained by other healers in a kind of 'apprenticeship' There seem to be no known 'entry qualifications' although undoubtedly the healers will know what they are looking for in a new student. Their skills are largely undocumented and jealously guarded. Their services are however easy to access within the community, and are administered by people who know the culture and customs of the



people they serve. Attah (1986) reports that the services are well used, unlike their Western counterpart, although they are not free. Odebiyi (1990) identifies the need to distinguish and classify the different types of traditional healers before assessing their effectiveness. He refers to Oyebola's (1980) seven types, including, diviners, herbalists, soothsayers, traditional pharmacists, bone setters and spiritual healers. He highlights the good reputation of the bone setters and birth attendants. Odebiyi (1990) estimates that only 35% of the Nigerian population have access to orthodox western systems of health care and reports a study which identifies 44% of western trained nurses as supporters of developing integrated services, traditional and western knowledge being used together. Evidence from Osifu (1992) indicates that traditional care includes treatment for disabled people including those with communication disorders, although the treatments described, seem, as in western medicine, to be associated with the individual/medical model perspective. Osifu (1992) describes herbal treatment for mental retardation, specifically Downs syndrome, which includes consuming a combination of the edible flesh of a boa-constrictor (known as 'Akpin' and also the name used for Downs syndrome children), with that of the giant snail and consuming this concoction 2-3 times per day. Osifu also describes treatments for people with epilepsy, hoarseness and strokes.

It was obvious to the researcher that a vast store of knowledge and detailed cultural perceptions remain relatively untapped and information about such practices would be valuable and important if appropriate and sustainable services for people with communication disorders are to be developed.

## 2.9.0 SUMMARY OF KEY ISSUES ARISING FROM THE SITUATION ANALYSIS.

1. Some facilities exist for people with communication disabilities in all areas of care. i.e.. health, education, social welfare, traditional care.
2. All services visited, with the exception of traditional practices, were originally established by NGO's.
3. Detailed policies exist at ministerial level in all areas mentioned, except traditional practices.
4. Policies and professional training follow an essentially Western model.
5. Although none of the policies mention people with communication disorders directly, all make provision indirectly for people in this category.
6. The actual implementation of the policies is limited.
7. There was very little evidence of any evaluation procedures and levels of accountability were poor.
8. The influence of the disability movement was apparent. There were a noticeable number of disabled people involved in pioneering services for disabled people.
9. Government input was limited. It involved policy making, staff salaries and training, but no running costs, initial development or evaluation. Evidence of co-ordination and monitoring was negligible.
10. There was a small amount of international input; this was not coordinated either with each other, or with national programmes.
11. There was evidence that perhaps around 2000 people received some sort of help from western based 'individual' model services either in terms of specialized medical attention, therapy or special education. The evidence came mainly from special education.
12. Community based services were referred to as 'traditional' practices.



**CHAPTER 3. DEVELOPMENT OF RESEARCH EXPECTATIONS  
AND HYPOTHESIS.**

*‘Far better an approximate answer to the right question..*

*than an exact answer to the wrong question.’*

*Tukey 1962.*

**3.1.0. BACKGROUND.**

During the process of the literature review and situation analysis, thirteen theoretical questions relating to people with communication disorders were developed. These questions fell into three divisions:

- communication disorders and disability
- communication disorders and wants and needs
- communication disorders and attitudes.

The relationship between these three issues and people with communication disorders form the basis of this research and underpin the development of the aims of this study. The thirteen questions are listed in the left hand columns of Tables 19, 20 and 21.

**3.2.0. SUMMARY OF INFORMATION RELATING TO THE 13 QUESTIONS.**

The information relating to these questions gathered from the review of the literature and situation analysis is summarized in Tables 19,20 and 21. These tables illustrate:

- the questions which were answered by information gathered in the review and analysis.
- those which provided a basis for discussion.
- those which remained unanswered and unaddressed and form the basis of this research

Table 19. Questions related to communication disorders and disability.

Questions posed	Summary of issues raised by the Literature Review and Situation Analysis.
1. Is disability (generally) viewed differently in less developed countries?	There seems to be evidence from the Literature review, Coleridge (1993) Kisanji (1995) Groce (1990) of both similarities and differences. Some of the differences relate to stages of development and similarities can be found between present day views in LDCs and views held in previous decades in More Developed Countries.
2. Can people with communication disorders, be considered as part of the co-hort of disabled people?	The Rationale developed from the literature for the terminology described in 1.2. would support this idea. There is evidence that there are advantages to developing consistency of terms (Enderby and Philipps 1986) thus increasing comparability and access. The concept of using the term 'people with communication disabilities' as a means of introducing a different perspective for the development of more social based terminology is supported by literature in the disability field such as DPI (1981) Swain et al (1993)and Finkelstein (1989).
3. Do people with communication disorders find themselves excluded from both disabled and able bodied groups by virtue of their communication difficulties?	Evidence from the situation analysis indicates that people with communication disorders find themselves among the group of people considered 'disabled' by authorities and communities which promote facilities to meet their needs. There was evidence to show some involvement of the parent's of children in this group, and from deaf and physically disabled people.
4. How can people with communication disorders speak for themselves? Could the deaf or parents be used as spokes people for this group? Could they help to express the wants and needs of other people with communication disorders?	There is a lack of evidence from the literature of people with communication disorders in LDCs expressing their needs and wants. Impairment related groups within their ranks appear to be divided by medical model perceptions and the idea that one group might speak for another is alien. There is evidence to suggest that parents try to represent their children's interests, particularly as founders and providers of services and NGOs, but it is unclear how well parents identify or express their children's needs and wants.



**Table 20. Questions related to communication disorders and wants and needs.**

Questions posed	Summary of issues raised by the Literature Review and the Situation Analysis
<b>5 .</b> Have the wants and needs of people with communication disorders in Nigeria and other LDCs been ascertained?	There was no indication that the needs and wants of this group had been ascertained inspite of WHO's (1981) emphasis on the importance of doing so for all health care services. The commonest method of establishing need through incidence and prevalence, are questioned by, among others, Helander (1993) and O'Toole (1995) but remain relatively unchallenged. The dangers of extrapolation are explored by the researcher and exposed by Coleridge (1993) and Saunders and Miles (1990).That the perception of need is affected by social parameters is observed by Enderby and Philipp (1986).Alternative ways of identifying need seem to be required.
<b>6 .</b> Are those wants and needs met by the services offered in less developed countries?	As the wants and needs are not known it is not possible to say if they are being met. However observation that prevalence levels are in excess of any kind of service provision, with coverage levels under 2% (Mba 1991, Marshall 1993, Helander 1993) and indications that centralized services, though limited, are underutilized, (Ransome-Kuti 1989, Miles 1985, McConkey 1996) are matters of concern. They raise questions such as, are the needs of the 98% the same as the 2%? Could the existing services be extended to meet the needs of a larger proportion? Would these services require a different delivery structure? or different training or both?
<b>7 .</b> Which kinds of service come nearest to meeting these needs and wants?	Not known, but differ according to situation.
<b>8 .</b> Does the fact that oracy is held in high regard and has an important place in Nigerian culture, make the observed disability of people with communication disorders / disabilities have a higher priority?	Observations made by Swann (1987) indicate that such perceptions exist in Rwanda, but no other documentation could be found to either support or refute this question. The situation analysis showed that the development of services has been based on a western model and as such mirrors the low priority given to this group of people in the development of services to help them.
<b>9 .</b> Could consideration be given to evaluating models of service delivery in the context of what people want and need as opposed to what people are getting?	The work of Saunders and Miles (1990) on the use of surveys would support this idea and the development of Rapid Participatory Appraisals to assess community health needs Annett and Rifkin, (1995) also provides a framework which could be pursued in relation to disabled people.



**Table 21.**  
**Questions related to communication disorders and attitudes.**

Questions posed	Summary of issues raised by the Literature Review and the Situation Analysis.
10. Are communication disordered people viewed differently in LDCs?	There appeared to be little evidence on this issue, only Akpati (1986) highlights a difference specifically related to people with communication disorders. Nothing was forthcoming from the situation analysis.
11. Do the different causes of communication disorders alter the attitude of people towards the person concerned?	There is evidence in the literature that there are different attitudes to the different impairment groups Nicholls (1993) Miles (1993) related to communication disorders, how much these attitudes are linked to a lack of ability to communicate, or the possible relationship between the ability to communicate and mental ability, is unclear.
12. Do the different attitudes and perceptions of disability in different cultures explain the various levels of observed or measured incidence and prevalence?	Information gathered in the literature Review would indicate that this was correct. See UN Compendium ( 1990 ) Coleridge (1993) Helander (1994)
13. Is disability a larger problem in LDCs than MDCs? Does this make it more imperative that meaningful action is taken?	Considering the impact of different perceptual attitudes it would seem that epidemiologically, disability may be a smaller issue while socially and economically, it may have greater implications. Coleridge (1993)

**3.3.0. RATIONALE FOR STUDY.**

The ability to communicate is a basic human need. This observation is supported by Helander (1993) and Mendis (1993) who report studies showing that disabled people themselves identify training in communication skills as a priority second only to the survival skills of feeding and cleaning.

We have seen from the literature review and the situation analysis that services specifically for people with communication disorders in less developed countries are poorly developed and those that do exist are poorly documented. The limited documentation, (see chapter 1.3. and chapter 2.), show that a predominantly western, medical/individual model of service delivery has been adopted, that its coverage level is extremely low, (Mba 1991, Helander 1993) and its sustainability impossible without western resources (Marshall 1994). The researcher observed that the lack of documentation, together with constantly changing personnel has allowed the same mistakes, in terms of service delivery, to be



made over and over again, (see section 1.3. for a review of service experiences.) With these points in mind investigation and documentation of issues concerning services for people with communication disorders is long overdue.

According to WHO (1981), assessment of need is a pre-requisite for planning and developing any health care service, it is therefore important to find ways of identifying the needs of people with communication disorders and use this information to develop new models of service delivery which have the potential for:-

1. Better coverage levels
2. Meeting those identified needs.

Investigation has shown that :

- incidence and prevalence surveys are commonly used to assess need in terms of numbers and demographic and pathological distribution. UN (1990)
- these surveys are expensive, time-consuming, nontransferable and often detract funds from service development. Enderby and Philipp (1986) Saunders and Miles (1990)
- these surveys give information about **numbers and impairments** e.g. Smith and Hatcher (1992) Amedofu (1993) National Population Census, Mauritius (1983) and do not address the actual and felt needs of the people themselves.
- alternative methods for assessing the needs of people with communication disorders in less developed countries are required, so that services can be planned and develop in such a way as to be appropriate and sensitive to the needs of the people concerned (Annett and Rifkin 1995).

Traditionally, disabled people are subdivided on the basis of medical criteria, that is according to their impairment category, e.g. hearing impaired, visually impaired, physically impaired etc. Logically, most groups will contain a certain number of people with communication disorders, as these impairment categories are also the main causes of communication disorders. Impairment categories have been used to underpin the development of rehabilitation delivery structures as rehabilitation expertise developed from a medical/individual foundation, for example, schools for the deaf or blind, clinics for cleft palates,



etc. As it is these service delivery structures which have failed to develop adequate coverage levels, and may also fail in terms of meeting the needs of those they serve, it is suggested that a re-categorization more closely associated with service needs and less connected to impairment categories, might provide the different perspective needed to develop service delivery alternatives.

It can be seen from the literature and the situation analysis in Chapters 1 and 2, that the ideology behind the equalization of opportunities and development of community services for people with disabilities is influenced by issues other than numbers or the type of impairment. Good practice within the disability movement bases its activities upon meeting identified needs such as:

- empowerment issues, Oliver (1990) Swain et al (1993)
- inclusion of community and family, Helander (1993)  
McConkey (1996)
- changing attitudes and improving knowledge Miles (1991).

Identification of the target group in this study proved problematic. The traditional terminology, 'people with communication disorders' was used in the initial stages of the data collection, (stages 1 and 2) but ongoing analysis of the data collected, illustrated the importance of moving away from an impairment or disorder base, and it was felt that the target group would be better described as 'people with communication disabilities'. This terminology was used as a basis for stage 3 of the data collection. This new terminology provides the basis for a different perspective, moving away from an 'impairment based' approach and opening the opportunity to become more 'needs based', as such, it encompasses a wider range of functioning for consideration in the rehabilitation process.

#### **3.4.0. AIMS OF PROPOSED DATA COLLECTION.**

The primary aim of this research is to use complementary qualitative and quantitative data collection methods, in two sub-Saharan African countries, to explore issues relevant to the development of appropriate service delivery structures and strategies, for people with communication disabilities, in less developed countries.



The issues seen as relevant to the development of appropriate and sensitive service delivery involve identification and clarification of terminology which will lessen confusion and allow comparisons between data to be made, movement away from impairment-led services and exclusive professionalism towards partnerships and enabling others to participate, and consideration of low coverage levels as a manifestation of poor standards of service. The research relates these issues to three key areas, those of disability, wants and needs and attitudes and aims to:

- look at people with communication disorders/disabilities regardless of impairment as a concept which encourages and allows for a wider perception of the factors involved, and explore these factors in relation to service delivery.
- explore an alternative way of measuring need which can be used as a basis for service delivery to complement or replace information gathered or extrapolated concerning incidence and prevalence.
- consider attitudes and knowledge about, and towards, people with communication disorders/disabilities, and the implication of these attitudes on service delivery.

### 3.5.0. HYPOTHESIS.

The issues seen as relevant have been identified by the literature review and situation analysis and are summarized in Tables 19, 20 and 21, It can be seen that they relate to three key areas:

- \* **disability** - moving away from impairment based terminology
- \* **wants/needs** - exploring the effective measurement of need and its application to service delivery.
- \* **attitudes**- investigating the impact of attitudes on service delivery.

With these issues in mind the research aims to address the hypothesis:

**Considering people with communication disorders as an identifiable cohort of disabled people, together with exploration of attitudes and needs, has major implications for service delivery and planning.**

In other words the identification of 'people with communication disabilities' unrelated to causal impairment grouping, together with consideration of wants needs and attitudes, has significant implications for service delivery development. It allows consideration of social issues which influence service delivery and training and are difficult to rationalize using a 'disorder' based model.



## CHAPTER 4. METHODOLOGY

*“It is better to measure what is relevant inaccurately  
than to measure accurately what is irrelevant.”*

*Black (1995)*

### 4.1.0. INTRODUCTION.

There are various arguments suggesting the need to use both quantitative and qualitative methodology in this study, for example:

- \* quantitative methods are more appropriate for testing the effectiveness of an intervention (Haines and Jones 1994)
- \* qualitative methods are more appropriate for considering meaning and interpretation (Barnes 1992)
- \* the ability to communicate is a socially interactive skill.
- \* by virtue of the relative rarity of communication disorders, research design options rarely offer the opportunity of large numbers.
- \* there are diverse questions associated with the service delivery issue.

These observations highlight the need to search for appropriate research methods.

### 4.2.0. RATIONALE FOR METHODOLOGY.

Purely quantitative research seemed inappropriate as it required a level of assumptions, preconceptions and focusing, incompatible with the aim of the study, and therefore one which would reduce its potential validity. On the other hand purely qualitative research can be seen to lack the rigour, credibility and reliability required both of a Ph.D. study and positive peer review. This dilemma seemed particularly relevant in health sector research where traditionally biomedical, quantitative methods are generally looked on with greater respect and receive greater emphasis in the training offered at the postgraduate level.

However Black (1995) points out, that health service research is in danger of pursuing the measurable rather than the relevant, and there is a tendency for measuring to start before a full understanding of the underlying issues is developed. Black (1995) argues and is supported by Mays and Pope (1995), that there are possibilities of developing rigorous methods within qualitative research which would be acceptable to quantitative researchers and allow more relevant studies to be carried out. Marshall and Rossman (1995) describe how qualitative methods can be combined using the strengths of one method to cover for the limitations of another and how sound defensible proposals for qualitative research can be developed.

In the light of the above information the observations of Haines and Jones (1994) seem particularly relevant:

“Traditional quantitative methods such as randomised controlled trials are the appropriate means of testing the effect of an intervention or treatment, but a qualitative exploration of beliefs and understandings is likely to be needed to find out why the results of research are often not implemented in clinical practice” pp 488.

It was therefore decided to develop methods which encompassed both qualitative and quantitative practices, supporting the idea of Pope and Mays (1993) that the two approaches are complementary rather than competitive, and that the distinction between them has created an unnecessary divide.

The overall process of this research, however, followed the philosophy of qualitative research methodology. This allowed consideration of wider, socially based issues and a process whereby much of the rigour rested with the integrity of the researcher. The flexible development process of the research was able to respond to information gathered in the process of data collection and used to modify subsequent stages of the data collection. These processes would not have been possible if a quantitative-led methodology had been adopted, where identification of a research question requires focusing down to a narrow field in order to control variables, a process which is valuable if and when appropriate questions have been identified, but one which is of less value when such



questions have not been formulated or are in subject areas that do not conform easily to biomedical science.

Although led by qualitative methodology processes, this research undertakes to develop methodology which includes complementary quantitative processes. Both types of methodology are used to address the issues identified in section 3. and are described in this section. These include surveys, interviews and group discussions, with professionals, parents and community members.

Bryman and Burgess (1993) suggest that researchers should not separate the stages of design, data collection and analysis, but go backwards and forwards between the raw data and the process of conceptualization, continually adjusting and readjusting their thoughts. Sections of the data collection developed from one another, eventually covering most aspects of the questions originally posed. It is difficult to pin point the exact stage at which certain concepts developed, and where others were rejected.

This developmental process was the reality of this research. For example the final survey involving community workers in Uganda, Survey 3, was designed as a result of the previous more qualitative studies and quantifies one of the key issues felt to underpin the pursuit of more appropriate service delivery structures, namely the importance of developing a different perspective on which to base the service delivery agenda. The flexibility of the research methodology enabled the development of theoretical concepts which, it is suggested, help to order the phenomena important to the development of appropriate service delivery and the related training.

For convenience and clarity, however, the presentation of the methods and subsequent results follow a more conventional demarcated structure.

### **QUALITATIVE METHODS HAVE BEEN USED IN THIS STUDY TO:**

- establish base line information
- identify priorities
- gather information and improve understanding which is used later to develop the content and wording of questionnaires.
- provide the basis for developing 'grounded theory', hypothesising inductively from data, allowing the use of subjects categories and concepts.
- contribute towards validation by the use of 'triangulation' where two or three methods are used and the results compared.
- use different research settings and different methods which include participatory involvement, semi-structured interviews, focus/discussion groups and surveys which have allowed access to different levels of knowledge giving a more comprehensive perspective.
- allow access to more complex phenomena or areas not amenable to quantitative research. Pope and Mays (1995)
- allowed for a wider range of methods to be available

### **QUANTITATIVE RESEARCH METHODS HAVE BEEN USED TO:**

- establish base line information
- quantify issues and phenomena identified by the qualitative research as valid and important issues within this investigation.

#### **4.3.0. TEMPORAL STAGES OF THIS RESEARCH.**

The data collection for this research took place in three stages and each phase of the data collection was modified and developed taking account of the findings of the previous phase.

##### **STAGE 1.**

This initial stage of data collection was ethnographic and qualitative in nature, taking the form of the literature review, situation analysis, participant observation and key informant interviews in Nigeria. It served to generate the hypothesis and inform the subsequent discussions and surveys.



## STAGE 2.

Stage 2 was conducted in Nigeria and included **group discussions** with parents on attitudes, beliefs and expectations. **Survey 1** looked at the knowledge and attitudes of student professionals. **Survey 2** gathered data from parents about service provision (coverage and quality) and identified needs.

## STAGE 3.

The researcher had left Nigeria at this stage of the research and to return to carry out final data collection seemed impractical and dangerous given the political unrest and the difficulties this posed. Advantage was therefore taken of the opportunity to access community workers in Uganda through contacts at the Institute of Child Health. This involved data collection from Community Development Workers through **Survey 3** to identify the proportion of people with communication disabilities who sought help from their services.

### 4.4.0. DESIGN

Given the social complexity of the subject matter it was considered essential to develop a research design which:

- used a mixture of qualitative and quantitative methods,
- developed a range of qualitative methodologies which responded to the evolving themes, at the same time as generating focus for quantitative methodologies.
- remained flexible to allow on going modification.

Consideration was given to the various methods suggested by Pratt and Loizos (1992) and Nichols (1991) and as a result four methods of data collection were identified. They were selected for the reasons indicated below:

1. Participant observation
  - establish well informed background information
  - identify questions, patterns and domains
  - monitor the execution and delivery of other methods.
  - inform questionnaire and interview design
  - inform theoretical model development

- 2. Key informant interviews - identify questions patterns and domains
  - inform questionnaire design
  - access local professional experience.
  - inform theoretical model development.
- 3. Group interviews.
  - observe collective response, differences and consensus
  - inform survey questionnaire design
- 4. Social Surveys.
  - quantify information about identified areas of concern.

The design of each of these methods is described in detail in the following sections.

A process of triangulation was used to establish validity of the data.

The methods were related to the three identified aims of the study stated in 3.4. The relationship between the method and the aims is shown in Table 22.

**Table 22 The aims of the study related to the various methods**

AIMS	METHODS
Consider ‘people with communication disabilities/disorders’ regardless of impairment as reality which encourages and allows for a wider perception of the factors involved and explore these factors in relation to service delivery.	Participant observation, Key informants, Group discussion, Survey 1, 2 and 3.
Explore alternative ways of measuring the needs and wants of people with comm. dis. which can be used as a basis for service delivery to complement or replace information gathered or extrapolated concerning incidence and prevalence.	Group discussion. Survey 2.
Consider attitudes and knowledge about and towards people with communication disorders and the implications of these on service delivery.	Participant observation. Group discussion, Key informants, Survey 1 and 3. Field notes of survey 3.

The three aims relate in turn to the three groups of theoretical questions. Explanation of the relationship between the original thirteen questions and the research methods is summarized in tables 23, 24 and 25 . Note that a number of the original questions were not addressed in this study. The reasons are given in the tables.



**Table 23. Questions relating to disability and methods of data collection used.**

Questions	Areas of data collection designed to address these issues.
1. How is disability (generally) viewed in Nigeria?	Participant observation Key Informants Survey 1B Group Discussion
2. Can people with communication disorders be considered as part of the cohort of disabled people?	Participant observation Key Informants Group Discussion Survey 1A and 1B. Survey 3.
3. Do people with communication disorders find themselves excluded from both disabled and able groups by virtue of their communication difficulties?	Key informants Participant observation Field notes of Survey 3. Group discussion
4. How can people with communication disorders speak for themselves? Could parents or deaf people be used as spokespersons for this group? Could they help to express the wants and needs of other people/children with communication disorders?	Key Informants Survey 2

**Table 24. Questions relating to wants and needs and data collection methods used.**

<b>Questions</b>	<b>Areas of data collection designed to address these issues.</b>
5. What are the wants and needs of people with communication disorders in Nigeria and other less developed countries?	Participant observation Group Discussion Key Informants Survey 2
6. Are those wants and needs met by the services offered in less developed countries?	Participant observation Group Discussion Key informants Survey 2 Survey 3.
7. Which kinds of service come nearest to meeting these needs and wants?	Participant observation Group Discussion Key informants Survey 2
8. Does the fact that oracy is held in high regard and has an important place in Nigerian culture, make the observed disability of people with communication disorders / disabilities have a higher priority?	Investigation of this issue required an in-depth study which was beyond the scope of this research. Recommended for further research and not addressed in this study.
9. Could consideration be given to evaluating models of service delivery in the context of what people want and need as opposed to what people are getting?	Key Informants Survey 2 Group discussion



**Table 25. Questions relating to attitudes and data collection methods used.**

<b>Questions posed</b>	<b>Data collection methods designed to address these issues.</b>
<b>10.</b> How are people with communication disorders viewed in less developed countries?	Participant observation Group Discussion Key Informants Survey 1A and 1B.
<b>11.</b> Do the different causes of communication disorders alter the attitude of people towards the person concerned?	Key Informants Survey 1A and 1B
<b>12.</b> Do the different attitudes and perceptions of disability in different cultures explain the various levels of observed or measured incidence and prevalence? A more focused question was developed and formed the basis of a small study - Do different professional groups perceive the degree of disability of disabled people differently?	Answered by information reported in the literature review. Not addressed in this study  Survey 1B
<b>13.</b> Is disability a larger problem in less developed countries than in more developed countries, and does this make	Answered by information reported in the literature review. Not addressed in this study

#### **4.4.1. PARTICIPANT OBSERVATION.**

This ethnographic approach was used along side quantitative and other qualitative data collection methods. The observations resulted in knowledge and skills which helped to formulate the direction, content and execution of this study.

Being part of the medical and educational services offered to people with communication disabilities over a period of 20 years in three different African countries, allowed the researcher to develop a wide perspective, which would have been difficult to acquire if the study had been confined to one place over a short period of time. This experience is continually drawn upon to facilitate the progress and direction of the study. Participant observation was used to develop the questions for the key informant interviews, group

interviews and survey contents as recommended by Kroger (1983) and was a source of inspiration leading to the conclusion that needs and wants could be identified by exploring attitudes and beliefs.

With the exception of Survey 1 Nigerian students and Survey 2 Nigerian parents, the researcher strove to maintain a participatory element to all the research activities in this study. Maintenance of this participatory role was seen as an important element in collecting qualitative data and also for monitoring the qualitative aspects of validity and smooth execution of the data collection. This participatory approach also served to maintain an ethical equilibrium, where all people participating in the study were able to receive information and advice.

## **PARTICIPANT OBSERVATION IN:**

### **The key informant interviews: Nigeria**

As the key informants were long standing colleagues of the researcher, it was particularly necessary to structure the interviews with them in a formal way, a time and place being set aside with a previously identified list of key questions, (see Appendix 3). This structure was used to minimise the bias that familiarity might otherwise have had, and to enable methodical records to be made of the data collected, thus improving the rigour of the method. It also allowed the informant opportunity to express his or her ideas in a structured yet free, empathetic, appreciative and respectful environment. The researcher believed that her local knowledge and familiarity with the informants enabled her to gather data in the form of opinions and ideas which would not have been easy for a visiting researcher to collect. This observation is supported by Cornwell (1984). It provided the opportunity for them to share their vision for service delivery options, based on long years of experience and involvement. The details of this data will be described in section 5.2.1. and 5.2.2.



### **The group discussions with parents: Nigeria**

The group discussions were conducted with four groups:

The first three groups were parents of children with communication disabilities attending Sabol International School. Participation with the staff of this school as a professional colleague, helped to facilitate this meeting and the group discussion.

The ~~fourth~~ group ~~was~~ a church related women's group and the meeting was organised by the researcher's housekeeper of long standing. Without this long standing trusted relationship, it is unlikely that this group of women would have agreed to share their views with someone from a different cultural background. The researcher believes that she was allowed to be part of this discussion because of this relationship. Participant observation was therefore an essential ingredient to this part of the data collection. The details of these results can be found in section 5.3.1 and 5.3.2.

### **Survey 1A and 1B. Student Professionals: Nigeria.**

These surveys were carried out within the professional field of health and education. They involved the completion of a questionnaire and could have been arranged and conducted equally effectively by a visiting researcher. Participant observation did **not** have a role in collecting this part of the data.

Previous participation in the local services offered to people with communication disorders did, however, contribute to the formulation of the 'scenarios' in the questionnaire, all of which were drawn from experience of 'real' people and described in a way that was likely to be locally understood. The details of these results can be found in 5.4.1. and 5.4.2. for Survey 1A and 5.5.1. and 5.5.2. for Survey 1B.

### **Survey 2. Parents of children with communication disabilities: Nigeria.**

Survey 2 was conducted after the parent's group discussion. The contents of the questionnaire cover utilization of services and identification of needs and attitudes. It is the opinion of the researcher that the development of this questionnaire required minimal previous participation in service delivery and could also have been easily carried out by a visiting researcher. This survey had no participant observation element in the collection of its data. The details of these results can be found in 5.6.1. and 5.6.2.

### Survey 3. Community workers: Uganda.

Survey 3 was conducted over a period of three months, together with 57 community development workers and their supervisors. The researcher was part of this team and participated in carrying out the research and also in providing information and advice to the community workers, and the people in the community. This provided a number of opportunities for participant observation. The details of these observations are reported in the field notes in appendix 14 and in sections 5.7.1. and 5.7.2.

#### 4.4.2. KEY INFORMANTS: NIGERIA

Semi-structured interviews were undertaken with four Nigerian professionals who had many years experience in striving to provide service for people with communication disabilities. They were chosen because of their wealth of experience and commitment by a process of theoretical sampling. The first three of these informants had been educated and trained in the 'west', the fourth had been educated within Nigeria, but in Institutions that had been developed on a Western model of education and training. The last two informants were disabled, one deaf and one physically disabled.

The informants were:

- An **E.N.T consultant** working at University College Hospital, Ibadan.
- A **Speech and Language Pathologist/Audiologist**, Headmistress of a private special school, primarily for pupils with communication disorders.
- A **retired Senior lecturer** from the Special Education Department of the University of Ibadan with impaired hearing.
- **Head of a Centre for disabled people** in Oyo State, and The Chairman of the National Council for Disabled People in Nigeria with a physical disability.



## INTERVIEWS OF KEY INFORMANTS

The interviews were semi-structured and were based around a predetermined check list of questions which can be found in appendix 3. The contents of the check list were developed around six areas of interest suggested by Patton (1987) and based on the researchers previous experience, namely:

- \*Behaviour or experience
- \*Opinion or belief
- \*Feelings
- \*Knowledge
- \*Sensory
- \*Background or demographic.

The list aimed to direct the gathering of information and contribute to a greater understanding and knowledge of the theoretical questions 1-7 and 9-11. The research bias was controlled by recording the interviews and making transcripts of the original data as suggested by Watzkin (1990). These can be found in appendix 11.

### 4.4.3. GROUP DISCUSSIONS: NIGERIAN PARENTS

Four group discussions were held, three groups were parents of children with communication disabilities, the fourth group were mothers who did not have disabled children and belonged to a church group. The discussions were designed to explore information related to questions 1,2,5,6 and 11. These focus group discussions were based around a number of questions which can be found in appendix 4 and encouraged group interaction to generate data and allow parents who might not otherwise contribute to share their ideas as promoted by Kitzinger (1994)

### PARENT'S DISCUSSION GROUPS

Parents of children who have communication disabilities discussed their beliefs and attitudes towards their children, and the situation and problems that they shared with them. The first three groups were made up of parents of children with communication disorders

attending Sabol International School. The fourth group were all mothers who were members of a church group who had no disabled children in their families.

Three of the group discussions were held at a parents meeting at Sabol International School Ibadan, Nigeria on 10 December 1993 from 5pm to 8pm. All the parents of children with communication disorders attending the school were invited. (details concerning the parents can be found in the survey 2 information in section 4.4.6.)

The meeting took the form of an introduction and explanation by the researcher, followed by the division of the group into three smaller groups of 6, 6 and 9 parents in each group. The largest group was the Yoruba speaking group. The other groups chose to discuss in English. The discussions were based round the checklist, see appendix 4, which was written on the school board for their consideration. The discussions took approximately 1hr 30 minutes and did not directly involve the researcher. It was not possible to record the interactions as all the groups functioned in the one room at the same time, so each group appointed a scribe to summarize their ideas.

### **COMMUNITY WOMEN (ALL PARENTS) DISCUSSION GROUP**

The fourth discussion group was with 6 women. They all belonged to a church group and were all mothers of non-disabled children. The same questions were used as a basis for discussion although some were obviously irrelevant and were omitted. The researcher was present and participated in this second discussion. The English of the members of this second group was not of the same standard as the first group and two of the members had to have some of the discussion translated into an Ebo dialect from time to time. The discussion took place on the verandah of one woman's home. The discussion was recorded and transcribed at a later date. See appendix 12 for transcription.



#### 4.4.4. SURVEYS: GENERAL CONSIDERATIONS.

Three surveys were carried out, two in Oyo State, Nigeria, and one in Eastern Uganda. The first two surveys in Nigeria **SURVEY 1** and **2**, will be considered together, and **SURVEY 3**, the Ugandan survey will be considered separately. It was decided to use **SINGLE CROSS SECTIONAL** type of surveys and where possible investigate **SUBJECT PERCEIVED DISABILITY** of the people with **COMMUNICATION DISORDERS**.

#### ISSUES FOR CONSIDERATION.

The social survey methods as described by Nichols (1991) were considered and choices were made in order to meet the needs of the presenting circumstances.

#### TYPE OF SURVEY TO BE USED.

It was decided to use a **SINGLE CROSS-SECTIONAL** survey because previous studies quoted by Ross and Vaughan (1984) indicate that this method can:

- help establish priority causes of the illnesses or disabilities
- identify different types of illness or disability
- determine attitudes towards the people with the disability
- determine attitudes towards the services offered.

These criteria meet the aims of the surveys.

In order to explore the different questions posed it was decided to design two surveys:

- one which looked at the knowledge and attitudes of the professionals involved in providing care for disabled people, including people with communication disorders.
- a second one looking at the attitudes needs and wants of the people needing help.

**GEOGRAPHICAL AREA OF STUDY** Oyo/Osun States, Nigeria. The rationale for using this area for the survey is similar to that already established in Chapter 2 for the situation analysis, namely:

- The people of Nigeria form 1/4 of the population of anglophone Africa, they are therefore representational of a large proportion of the people in question.
- It is a manageable size geographically.
- It is an area where the researcher has contacts both with professionals and people with communication disorders.
- Oyo and Osun State have a long history of western intervention. Western services have therefore had plenty of opportunity to become established.
- The population of Oyo and Osun States compares in size with the population of other Anglophone African countries. It is larger than Botswana, Gambia, Lesotho, Liberia, Mauritius, Namibia, Seychelles, Sierra Leone and Swaziland. Smaller than Zambia Zimbabwe, Malawi.

**MAJOR OBJECTIVES** To gather information concerning professional knowledge and attitudes towards people with communication disorders, with a view to using this information in health planning for the development of appropriate services for people with communication disorders.

**REFERENCE POPULATION** Professionals in training and parents of children with communication disorders in Oyo and Osun States Nigeria, representing similar populations in Anglophone Africa.

**SAMPLING DESIGN** random sampling from selected group

**SAMPLE SIZE** The sample sizes were small because:

- Limitation of access to large numbers of such a select group.
- Limitations of resources in terms of manpower and time.

**INTERVIEWING AND MONITORING** was done by the researcher only, and similar procedures were used with each group, thus limiting the possibility of variation in the presentation.



**IDENTIFYING THE RESPONDENTS** The respondents were identified and recorded in each case. When parents are responding on behalf of their children this is recorded.

**IDENTIFICATION OF THE RECALL PERIOD.** The recall period was likely to be of a long duration and this was considered unavoidable due to the nature of the problems under investigation. Recognition of the inaccuracies which may be represented here due to failure to recall accurately after long periods of time will have to be taken into consideration when interpreting the results.

**CONTENT OF QUESTIONNAIRES** The questions for survey 1 and 2 emerged from the participant observation aspect of the research as recommended by Kroeger (1983). Details of the questionnaires are supplied in the Appendices.

**VALIDATION** Validity of the data was established by triangulation

**SUMMARY OF RESULTS** The results of the different methods of data collection are reported in Chapter 5.

## **LIMITATIONS OF THE STUDY.**

The study was limited by:

- A restricted budget. The costs of this study were met by the researcher's personal funds, raised from employment with the National Health Service in Norfolk County, UK.
- It is recognised that the researcher as participant observer was involved in providing local services which created opportunity for bias due to personal involvement. Well defined methodology was used to minimize this.
- Strikes and Political unrest in Nigeria limited data collection and information gathering for the situation analysis, for the key informant, group discussions and surveys.
- The data is gathered in 2 Anglophone African countries based on experience in 5 Anglophone African Countries. Generalization to other less developed countries may be questioned.
- Sample sizes were small due to limited time, funds and availability of suitable subjects.

#### **4.4.5. SURVEY 1 STUDENTS KNOWLEDGE AND ATTITUDES IN NIGERIA.**

##### **AIM**

Survey 1 is designed to gather information on how different student populations in Nigeria view people with communication disorders. The questionnaire aims to look at the perceived severity of the disorders causing communication problems, and the perception of the levels of disability experienced by the people who suffer in this way.

##### **HYPOTHESIS**

Different professional groups have different attitudes towards people with communication disorders. Medically orientated professionals have a more disabling attitude and perceive disabled people as more disabled than other groups.

##### **SUBJECTS**

The questionnaire is given to four different groups of students, representative of different areas of knowledge and possibly attitude, but sufficiently similar in age, general educational level and social and cultural background to provide some homogeneity. The students' knowledge and associated attitudes were chosen as representational of current thinking in the educational system available in Nigeria and also because they were accessible to the researcher.

**Group 1.** represented young people in Nigeria who are undergoing education and training in a field related to the health care of people with disabilities. i.e.. Student nurses.

**Group 2.** represented young people in Nigeria who are undergoing education and training in a field related to the education of people with disabilities i.e. student teachers of special education.

**Group 3.** represented the views of young disabled people in Nigeria. i.e. disabled student teachers of special education.

**Group 4.** represented young people in Nigeria who were undergoing education and training in a field unrelated to disability. i.e. agricultural students.



## SAMPLE SIZE.

The small sample size was dictated by the limited numbers available for two of the groups, i.e. disabled student teachers, and agricultural students. Initially it was hoped to find at least 20 for each group but the final sample numbers were:

Group 1. student nurses. 20

Group 2. student special education teachers 20

Group 3. student special education teachers who were disabled 10

Group 4. student agriculturalists 13.

As it was the first time this tool had been used, the data collected provides a basis on which further sample size could be calculated.

The questionnaire was constructed so that it could easily be completed by a group of students in under fifteen minutes. Analysis of the responses of the groups to the questionnaire was designed to reveal the:

- Perceived rank ordering of the severity of the different underlying causes associated with communication disorders and resulting disability.
- The similarities and differences between the responses of the groups.
- Information concerning how people with communication disabilities are perceived.
- Reliability of the questions.

## DESCRIPTION

Survey 1 was designed in two parts, A and B.

Part A asked the person completing the questionnaire to list the perceived severity of communication disorders. The communication disorders were categorized by the different causative impairments with which they are associated. The ten causative groups were adapted from the 18 disorder groups identified by Enderby and Philipps (1986) by amalgamating the rarer conditions under more general headings such as degenerative disorders and voice disorders and also by combining head injury with Cerebro-vascular accident. (CVA.) See literature review for details. The ranking choice was made from a closed list.

Survey B presented twenty scenarios. Each scenario gave information about the age, sex, type of disorder, underlying pathology, and finally a description of the communication functioning in a similar length of text.

The same ten categories of communication disorders were represented in the 20 scenarios, each category was represented twice. Twelve of these scenarios described expressive disorders, one a receptive disorder, and seven cases were both expressive and receptive. A copy of the final version of the questionnaire can be found in Appendix 5.

The person completing the questionnaire was required to rank order the scenarios according to how they perceived the degree of disability described. Categories of disability were ranked into one of six possible groups ranging from 0 - 5. 0 representing no disability, 5 representing very severe disability.

Table 26. illustrates how the various variable criteria were distributed in relationship to the categories of disorders. For example, the first scenario concerned with mental handicap was a male child with a severe disorder, while the second case was an adult female also with a severe disorder. As it can be seen from the chart there were ten examples of each criteria.



**Table 26.**  
**Criteria and Categories represented by the questions.**

C r i t e r i a						
Categories	Male	Female	Child	Adult	Mod	Sev
M. Handicap	1	X	1	X		1X
Deaf	X	1	1	X	1	X
Stammer	1	X	1	X	1	X
Stroke/head I	1	X	X	1		1X
Cleft Palate	X	1	1	X	1	X
Cerebral Palsy	X	1	1	X	1	X
Voice Dis.	1	X		1X	X	1
Pre-School	1	X	1X		X1	
School	1	X	1X		1X	
Degenerative	1	X		1X	1	X
	10	10	10	10	10	10

1 - First case in that category.

X - Second case in that category

At the end of the questionnaire there are two questions aimed to gather information about the person’s perception and attitude towards people with communication disorders and the associated level of need.

**PILOTING OF SURVEY 1A and 1B.**

The questionnaire was completed by a Speech Therapist and a College Lecturer.

**The following observations were made:**

- Both completed the questionnaire in 10 minutes.
- As a result of their comments some modifications were made to the original version, namely:
  1. Additional explanations were added for cerebral palsy, degenerative disorders, cleft palate and school children who do not speak or understand properly.

2. A more detailed explanation for the initial grading process was added, including the phraseology, “ the amount of human suffering they are likely to experience and the effect this will have on their relationships with family and friends.”

3. Two questions were added at the end of the questionnaire to try to target the attitude towards the causes of communication disorder, basically “science,” versus “God’s will.” Care was taken not to word the questions in such a way as to preempt the outcome. The result were:

- Why do you think some people cannot talk or understand?
- Should people who cannot talk be left alone and accepted for what they are, or can they be helped by medicine or by teaching to speak and understand better?

Circle the answers which you think apply.

Left alone. Accepted Helped by medicine. Helped by teaching

A copy of the final questionnaire can be found in Appendix 5

## DATA COLLECTION.

**Group 1.** The questionnaire was administered to 20 third year student nurses training at Ibadan University College Hospital Ibadan on 27.1.93 . These students were receiving a tutorial at the time of our visit, the year group was 63 students divided into three tutorial groups of 21 students in each. The supervisor was prepared to let us have access to these students for 20 minutes, but was not happy about a random selection from the whole group and this would have disrupted the time table, even though previous arrangements had been made. It was decided to carry out the survey with the tutorial group that was available. One student arrived 15 minutes late and she was excluded from the survey.

**Group 2** The altered questionnaire was then presented to 20 third year special education students at Oyo Federal College of Special Education, Oyo State, Ibadan, on 14.1.93. The random selection of the 20 students was made from 600 students who were attending



a core course on child development psychology. The matriculation numbers of these students began at 02507. A system of selecting every 10th student until 20 students had been selected was adopted. If a selected student was absent, then selection proceeded to the next 10th student. Effectively 20 students were selected from 290 students, matriculation. numbers 02507 - 02797.

**Group 3** The questionnaire was given to 13 Agricultural students who were from a group of 40 students attending The International Institute of Tropical Agriculture, Ibadan, on Post-graduate studies. The 13 students who completed the questionnaire were by self selection because:

- It was hard to organize students to meet together in one place at the same time.
- Many of them travelled regularly and operated independently.
- The students who were approached were not keen on giving information, particularly if they had to identify themselves.
- It is possible that this group of students found the questionnaire threatening, perhaps because many of them did not come from Nigeria and felt vulnerable in another country.

The information from this group has been included in the research evaluation but it must be remembered when interpreting the results that the group was :

- not representative of Nigeria but from all over Africa.
- not undergraduate students.
- not from the same age range as the other groups. (23-45) instead of all in their 20s

These discrepancies were observed at the time and it was felt important to look for a group of Agricultural students from Ife or Ibadan University who might be more suitable. Attempts were made to do this in January 1993 but as the Universities were on strike at the time, this proved impossible. On a further visit to Nigeria in October 1993, the country, was experiencing considerable unrest due to the annulment of the election results; carrying out such a survey became impractical. It was therefore decided that the original data from the postgraduate students should be used, but that a note should be made of the limitations of the data.

**Group 4.** At the same time as administering the questionnaire to the students of special education, 10 disabled special education students were selected, five deaf and five blind. These were the ten disabled students attending the lecture that day, and are self selected from the 16 disabled students thought to be registered in that year. It was thought that there was a potential total of 16 disabled students in this class of 600, but this information did not appear to be reliably documented. During the course of the lecture two additional disabled students arrived late; they were not included in the survey.

A short explanation was given to all the students concerning the purpose of the questionnaire and their responses were completed without collusion. They were permitted to ask for clarification of any part of the process. All four groups completed the questionnaire in 15-20 minutes.

#### **4.4.6. SURVEY 2. PARENTS OF CHILDREN WITH COMMUNICATION DISORDERS IN NIGERIA.**

##### **AIM**

The aim of this survey was to gather information about the wants and needs of children with communication disorders by asking their parents to identify their needs and give information about the utilization of services.

##### **SUBJECTS**

The questionnaire is designed to be completed by the parents of children who have communication disorders. The children were pupils attending a private special school for children with communication disorders run by a Nigerian woman who is an American trained Speech Pathologist and Audiologist. For more information see key informant interview number 2 in chapter 5. Information from the literature review indicated that the different perceptions, of and towards, the different disability groups, would make it difficult for one disability group to speak for or represent another, so it was decided to use the parents as spokes-people for their children, although it was recognised that this too would have its limitations.



## DESCRIPTION

A questionnaire was developed with 20 questions, a copy of the questionnaire can be seen in the Appendix 6, The questionnaire aimed to gather information about the utilization of services and wants and needs.

## PILOT

Circumstances involving a lack of time and opportunity prevented a pilot run with this questionnaire.

## DATA COLLECTION.

38 of the 52 children attending Sabol International School in Ibadan Nigeria, had a communication disorder, i.e. 72%. There was a possible total of 38 children and to our knowledge 76 parents, although the school did not hold information about the existence of all the parents. All 76 parents were invited to attend a group discussion meeting at the school; the questionnaire was completed by those who attended. The questionnaire was completed by 26 parents of 28 children with communication disorders who were attending the school. In two cases both parents attended and four of the parents who attended, had two children with communication disorders attending the school.

## 4 4.7. SURVEY 3. COMMUNITY DEVELOPMENT WORKERS IN UGANDA.

### AIM

The aim of this data collection is to establish whether people with communication disabilities are an identifiable group of people seeking the help of community based rehabilitation services.

## HYPOTHESIS

People with communication disabilities form a significant proportion of the disabled people seeking help from community development workers in Eastern Uganda.

Survey 3 is conducted in Uganda separately from the other surveys and so details concerning its development have been considered separately.

## **TYPE OF SURVEY**

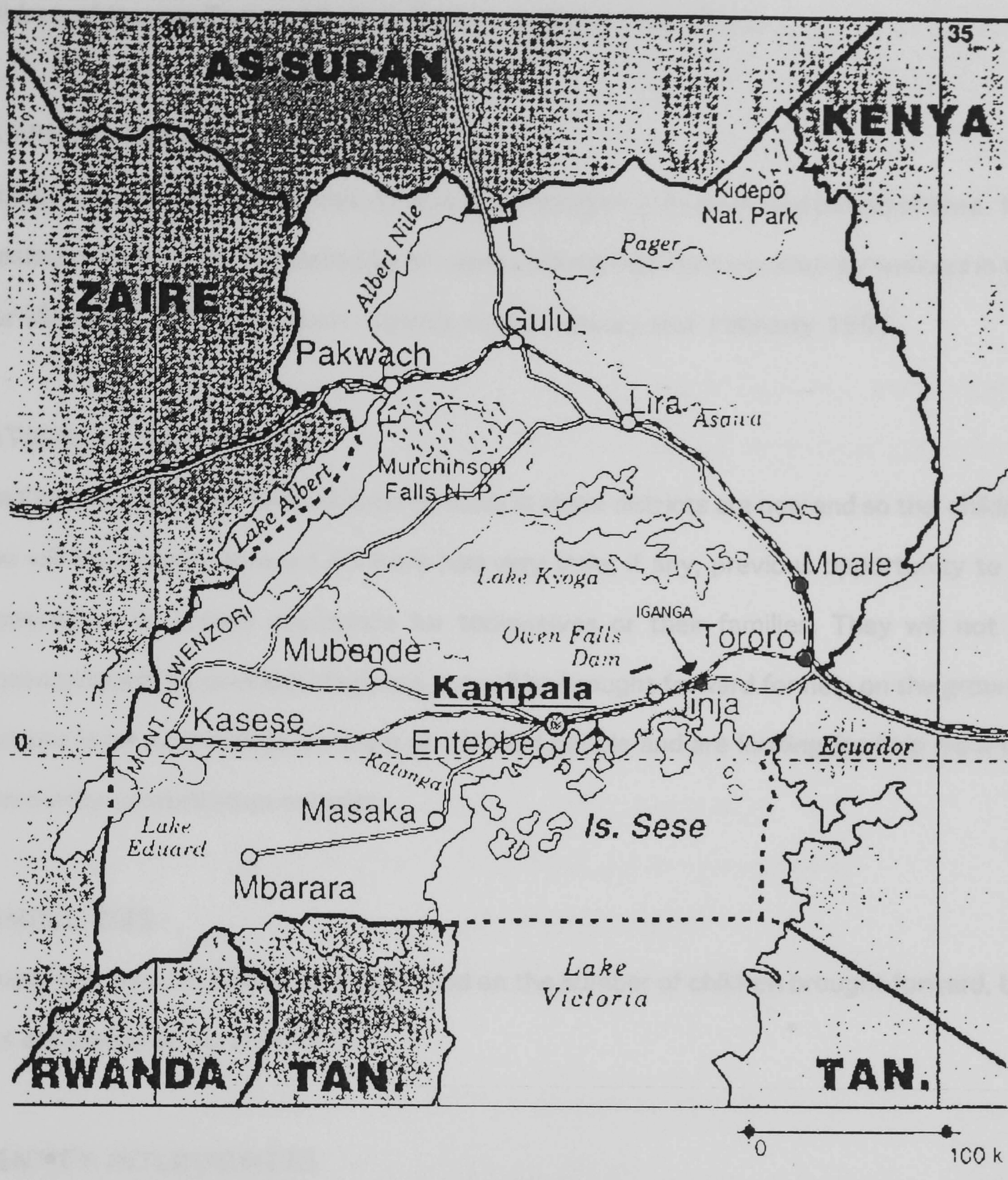
This Social Survey was constructed by adapting and expanding the four communication related questions found in the “Ten questions” developed by Zaman and Kahn et al (1990). They successfully used the ten questions to identify people with disabilities in Bangladesh. The questions address issues related to impairment and functionality and conform to the WHO (1981) definition of disability. The four questions about communication were extracted and used as a basis from which other questions are created and added. The questions which were developed attempted to embrace a slightly wider perception of communication disability in that they include elements of social interaction e.g. question 10, as well as impairment related, e.g.. question 7 and disability related e.g. question 5. The questions were used to identify the existence, or otherwise, of a communication disability in children when they first present themselves to community based rehabilitation services.

## **GEOGRAPHICAL AREA**

The survey was held in the Iganga, Tororo and Mbale districts of Eastern Uganda. Illustrated in the map in Figure 4.



FIGURE 4. MAP OF UGANDA



## DATES.

The survey was conducted in January and February 1995

## MAJOR OBJECTIVES

To gather information concerning the percentage of children with communication disabilities who looked for help from community development workers (CDAs), and to establish them as a percentage of the disabled population.



## **REFERENCE POPULATION**

Children of Iganga, Tororo, Mbale in Eastern Uganda, East Africa.

## **SAMPLING DESIGN**

Purposive theoretical systematic continual sampling over an identified period of time. The questionnaire is to be completed by all cases seeking help from community workers in the four identified areas of Eastern Uganda during January and February 1995.

## **RATIONALE FOR DESIGN.**

The Community Based Rehabilitation services in these districts are new and so the children who will be brought forward will have had very little, if any, previous opportunity to be assessed or to access assistance for themselves or their families. They will not be “contaminated” by previous diagnosis but will be brought forward for help on the grounds that the local people observe them as disabled people and are looking for help from the community rehabilitation services.

## **SAMPLE SIZE**

Initially this was not known as it depended on the number of children brought forward, but was estimated to be at least 500.

## **IDENTIFY INTERVIEWERS**

Community Development Assistants (CDAs) workers within the community services of Eastern Uganda.

## **IDENTIFY RESPONDENTS**

The respondents were disabled people and their families and carers who looked for help from the community-based rehabilitation services of Eastern Uganda.



## **CONTENT AND DESIGN OF QUESTIONNAIRE.**

The questionnaire included Biographical data: Community worker, Child's name, Accompanied by, Child's address (village, area.) Sex, Age. Plus the Zaman and Kahn's (1990) modified and extended "ten questions" to identify disabled children who have a communication disability see appendix 8.

## **PILOT.**

The Original questionnaire was piloted with the initial group of CDAs from Mbale at their training in Tororo. As a result of this piloting minor changes were made and the final version can be found in Appendix 8.

## **RELIABILITY.**

Methods to establish reliability :-

1. Meet and train groups of 15 community development assistants (CDAs) in Kampala when on initial training course. Three groups, one for each district.
2. Visit every third CDA, check daily routine, check use of questionnaire.
3. Re-test 20 randomly selected cases and compare results.

## **SUBJECTS**

The subjects were self selected and identified themselves by seeking help from the community based rehabilitation services of eastern Uganda.

## **DESCRIPTION**

Prior to travelling to Uganda a timetable was discussed and formulated in conjunction with Mr. Jackson Mirembe, Chief Rehabilitation Officer in the Ministry of Local Government. (This service moved to the Ministry of Gender and Community Development during the course of this study.) On arrival in Uganda in November 1994, when contact was made with Mr. Jackson Mirembe, it was immediately obvious that the original plan would have to be altered as several factors had changed since the original timetable was drawn up.

1. The training was taking place in Tororo, not in Kampala as was originally planned.
2. Due to limited funding there were 3 groups of CDAs in training, from three districts instead of the original 4. The Districts were Iganga, Mbale, and Tororo.
3. Each of these groups had increased in number from the original 15 CDAs to include local representatives from Non Government organizations to a maximum of five extra people, making up three groups of 20.
4. The first phase of the training for the CDAs was nearing completion, and the final group, from Tororo were still in session.
5. The next phase of training would take place in March.

In the light of this information an appropriate programme was drawn up.

## PROCEDURES

1. It was decided to train the three groups in the use of the questionnaire as soon as possible.
2. It was decided to ask the CDAs to collect the information over a period of two months, January and February.
3. It was decided to monitor the procedures by randomly selecting a number of CDAs and making a visit to their home area. Monitoring would take the form of:
  - visiting them at their own place.
  - identifying any problems they may have had in carrying out the questionnaire and documenting this.
  - Randomly selecting a case they had already seen and visiting it personally and conducting a repeat questionnaire for comparison with the original questionnaire already completed.
  - talking to families that needed help or advice.



## **Final Programme**

### **December 1994**

- Visited the training course for the Mbale CDAs. Considered the questionnaire in the light of local information and made the necessary adjustments as recommended by this group's observations. Trained CDAs on how to carry out the questionnaire. Listed all CDAs at the training session, see Appendix 7 Handed out 20 questionnaires to each CDA.
- Met with the Community Rehabilitation Officers (CROs) of the other two districts and made arrangements for a special meeting with the Tororo and Iganga CDAs.
- Trained Tororo and Iganga CDAs, see Appenix 9b and 9c, making a total of 57 trained CDAs in the three districts.
- Took the three lists of the CDAs participating i.e. those who had been trained, put the names into alphabetical order and selected every 4th person. (14 CDAs) Made a list of these people in preparation for making arrangements to visit them in February, see Table 37.

### **January 1994.**

- Visited the three district headquarters early in the month.
- Met with the CROs and the Community Development Officers (CROs) together with the CDAs to check for any difficulties with the questionnaire and to rectify if possible.
- Informed them of the selected CDAs to be visited and made arrangements for the dates and logistics of these visits.

### **February 1994**

- Visited each of the three areas together with the CRO and CDO.
- Visited each of the 14 randomly selected CDAs and carry out the monitoring process.

### **March 1994**

- Visited each of the three area headquarters to collect all the completed forms and thank the CROs, CDOs and all the CDAs for their participation in the programme.

The actual timetable for collecting data can be found in Appendix 13 and the field notes covering these visits in Appendix 14.

## CHAPTER 5. RESULTS AND ANALYSIS.

*‘Where is the understanding we have lost in knowledge?’*

*Where is the knowledge we have lost in information?’*

*Choruses from “The Rock” by T.S.Elliot.*

The results are presented from a variety of sources, namely participant observation, key informant interviews, group discussions and surveys. These methods of data collection have been described in detail in Chapter 4, under Methodology.

### 5.1.0. PARTICIPANT OBSERVATION.

The participant role in this study is executed in two ways, as defined by Barnes (1992), the ‘participant as observer’, where the researcher and the researched are aware of the field work relationship, and the ‘observer as participant’ referring to the researchers role during the interviewing process.

### 5.1.1. RESULTS (KEY OBSERVATIONS) FROM PARTICIPANT OBSERVATION.

Seven key observations were developed from participant observation. These observations and their derivations are given in the eight boxes below:

#### **1. The check lists and questionnaires used in this study were developed as a result of participant observation.**

- The check lists for the key informant interviews and group discussions were developed from interaction with other professionals and with parents. These discussions identified key areas of concern expressed in conversation by these groups of people.
- The scenarios in Survey 1 were all developed from adapting descriptions of real people, seen in clinics, schools and local communities in Nigeria, Kenya and Lesotho.
- The adaptation of Zaman and Khan’s (1989) 10 disability questions into 10 communication disability questions was influenced by questions developed in clinical interviewing practice in Nigeria Kenya and Lesotho



**2. It seems better to consider people with communication disorders as part of the cohort of disabled people as it enables access to more appropriately developed services and locally gathered, more culturally appropriate information.**

- Over a period of years, it was observed that provision of services for people with communication disorders seemed to be consistently more appropriate and sustainable when provided as part of a service structure associated with disability than when part of general health care services. cf. Thriving School/Units for Deaf Children in Kenya versus the demise of clinical provision at Kenyatta Hospital in Nairobi.

- Extrapolation of data from international surveys did not appear to be compatible with local observations e.g.. a much higher rate of otitis media and its associated problems were observed in the Kinangop area of Kenya in the 1970's than extrapolated data of the time would indicate, and a much lower rate of the same condition was found in Oyo State, Nigeria in the 1980's.

- The general lack of facilities often resulted in services developing to meet the needs presented, rather than the other way round. Thus schools accepted a mixture of disabilities regardless of the institution's declared interest, this could have been due to a combination of limited differential diagnosis ability and a more pragmatic view of disabled people in general.

**3. There are a number of dedicated and knowledgeable local people involved in providing services for people with communication disorders. These local experts need support for their ideas and strategies, not interference or superimposed systems based on services in other countries with people from cultures at a different stage of development.**

- In all the countries that the researcher has worked, Kenya, Lesotho, Seychelles, Uganda and Nigeria, she has been privileged to identify and work with local people from whom she has learnt a great deal about the local culture and its influence and role in the communication process.

- She has learnt that no service can ignore cultural perceptions and sustain activity and that it is essential to build services on existing knowledge and structures. e.g. A School for the Deaf established by the researcher within the framework of a local mission in Lesotho, despite many difficulties, is still running, whereas 'western' 'medical model' services depending on a VSO Speech Therapist in Uganda and Kenya have ceased to exist when the VSO departed.

- The Researcher has learnt to respect and admire the efforts of local people and recognise with humility that she has undoubtedly learnt more from them, than they may have done from her.



**4. Services for people with communication disorders are very scarce in less developed countries and not always appropriate to the need.**

- The Researcher has lived and worked in 5 less developed countries over a period of 25 years and in every country, services for people with communication disorders have been scarce and underdeveloped.
- The services which did exist were urban based and often reached very few of those in need. They tended to address the needs of the urban elite.
- Services were sometimes so removed from the everyday life of the person seeking help that they were inappropriate. e.g.. supplying hearing aid when there was no back up service or no local facilities for obtaining batteries. Recommendations concerning schooling were not based on full history.

**5. Cultural and linguistic expectations and knowledge alter the emphasis of what might be considered helpful, so much so, that it is impossible for professionals from other cultures to function positively without considerable assistance and cooperation of local experts. This supports the development of long term cooperative programmes.**

- Observations by the researcher during clinical practice such as:
- Kenya children are not expected/allowed to look at their elders, making lip-reading an impractical option.
- It is unacceptable to express problems to people outside the family in many African Cultures. This affects interviewing techniques and expectations.
- A perception that the inability to speak removes the 'soul' of the child in Nigeria.
- These issues all effect service delivery and development.

**6. Lack of coordination between the parties involved results in wasted efforts and resources.**

- In Nigeria, for example, professionals and service providers are often totally unaware of other services offered in the surrounding areas. This often results in duplication and mismanagement of services.



**7. People with communication disorders form a significant proportion of the cohort of people who are considered disabled.**

- Participant observation through visits to special schools and institutions for disabled people over many years in Nigeria, Kenya and Lesotho revealed a high proportion of people with communication disorders within their ranks.

**8. What people need and want is often expressed through their attitudes and beliefs.**

- People often expressed their faith in God and western medicine, observation of the consequences of these beliefs did not seem to be well founded. Invariably they would be disappointed on both counts.

- Many parents and families were so grateful for simple ideas and small simple pieces of knowledge. Their grateful attitude was overwhelming on occasions.

#### **5.2.0. KEY INFORMANT INTERVIEWS.**

The interviews were conducted with four key informants who were all colleagues of the researcher. Interviews were based around a check list of questions. The bias created by the familiarity of the informants with the researcher was controlled by the structured methodology but at the same time provided an unusual opportunity for frank discussion and responses. Details of the informants and the methodology used can be found in the methodology section 4.4.2. and transcriptions of their interviews in Appendix 11.

#### **5.2.1. RESULTS FROM KEY INFORMANT INTERVIEWS.**

Three of the four interviews were recorded and a transcription of these interviews can be found in appendix 11. It was not possible to record the interview with Prof. Ijaduola due to air conditioning noise and many interruptions, but a summary of all the interviews is given in this section. The information recorded in the interview with Dr. Mba was shorter than the other interviews possibly due to the linguistic complications arising from the use

of sign, speech and an interpreter. Some of the interviewees keep closer to the predetermined check list of questions than others. This freedom to express ideas about the issues they considered to be important, led to some variation in the topics covered, but at the same time allowed the discovery of issues not previously considered by the researcher.

**RESUME OF THE INTERVIEW ON 2.11.93 OF MRS. FUNKE SABAGE, SPEECH PATHOLOGIST /AUDIOLOGIST AND HEADMISTRESS AT SABOL INTERNATIONAL SCHOOL, IBADAN, HELD IN HER OFFICE.**

**The full transcript of this interview can be found in Appendix 11a.**

Funke had wanted to be a medical doctor but she was influenced by a friend who was deaf. This friend enabled her to see the shame of the Yoruba people towards those who were deaf, “*they would always ask her to go and stay in (another) room when visitors come*” Funke was counselled to study Speech Pathology and Audiology and given information on the training available in the United States. She trained at Temple University and Galludet College, a College for Deaf Studies, returning to Nigeria in 1986. She wanted to work with young people and their parents but she could not persuade University College Hospital in Ibadan, where she worked, to initiate a preschool parents’ programme. She worked at UCH for over a year doing mainly Clinical Audiology and counselling. Eventually she was persuaded by one particular mother to start a family programme and opened a small ‘school’ with 4 pupils in 1987. This soon increased to 7, 5 deaf children and 2 with ‘speech problems’ Her school now has between 80 - 100 children, this fluctuates and was more when they were running transport and picking up the children (Around 60% are ‘special’ in that they have some sort of communication disability and 40% of the children are ‘normal’- information from previous interview.) They include her own children.

Some parents are putting pressure on her to develop boarding facilities but she doesn’t want to develop too many boarding places as she feels that parents should be involved and children need to grow along with their families.



Funke would like to have services develop in the community, *"my own idea is that these children should grow up within their own families"* *"I would like to have something that is in the community, accessible to the people"*. She does not feel that centralised services are acceptable and that is one of the reasons she left the hospital. She feels *"things attached to the government (in Nigeria )don't work very well"* particularly services for disabled children. These *"services need dedication"* *"you need people that can stand behind it and make sure that it works"*, people who are prepared and able to give continuous service over a long period of time.

- She feels that someone needs to take the *"BURDEN"* but not necessarily the government.
- She feels that you should bring training to the people with local training.
- Locals should be involved in the training, they should be asked *"what is it that you want to do?"* *"What services do you want to render?"* *What is your own idea of the whole thing?"*
- They then need to be helped to develop their own ideas.

The words for 'deaf ' in Yoruba are all negative in meaning adding to, or reflecting the negative attitude associated with such people, e.g.. 'Alabu' also means disgraceful, a bad mark, 'abirun' means 'needs help.'

Traditionally, in Yoruba culture, the whole family is to blame for a disabled child, *'sometimes the mother takes the largest share of the blame '* and *"traditionally they try to get rid of the child"*. Some disabilities are viewed as worse than others, for instance, the deaf are more acceptable than the physically impaired. Mental impairment is the least accepted. *"The worst type of handicap is one that affects communication as traditionally society holds verbal ability in very high stead."*, it is very important for social functioning.

If a person is not too handicapped people *"would rally round and help."* There is age group support which is very strong and fellow members of this group would often undertake to see that the person with a disability is not left out. In urban areas the community structure

has been disrupted. For instance if you are expecting a baby and live in a traditional community you would not be expected to do anything for three months, mothers and sisters would support you. In urban society you just have to continue working *“I have to do everything by myself”* (Funke was expecting another child due ‘any day’, so these remarks were made with a great deal of feeling.) In the past disabled people in rural areas had a better deal than they do now. They were supported by the community system. In the past, no family would want to find their own family member begging. Family pride supported the disabled person with food, shelter and care. They would be taken to the traditional doctor, maybe the herbalist or the spiritualist. *“So development is sometimes backwards.”*

Disability does affect rank and inheritance, *“but it shouldn’t.”* The Yoruba culture believes that disabled people should have rights like other people. In practice this is not always the case. Rank is inherited, not generally achieved by education or expertise, but this is changing. Traditionally in Yoruba culture, there would be a woman in the village who would be a sort of Goddess for the disabled and she would look after them. A person can be blamed for his disability, can be ignored and avoided and refused work.

Funke feels that the best help available for disabled people is in rural areas, here they will be looked after and there is always someone around. In cities many people go out to work locking up their handicapped child to keep them safe, but Nigerian people do not easily accept that they have the answer within their own system and community.

Most people in Nigeria, *“do nothing”* to help people with disabilities, but the ones who want to help are *“always looking for something BIG and grand”*, and for disabled children, if they can afford it, they want to send them to boarding school.



## RESUME OF THE INTERVIEW WITH PROFESSOR G.T.A. IJADUOLA. E.N.T CONSULTANT. UNIVERSITY COLLEGE HOSPITAL, IBADAN. ON 13.12.93.

The Professor did his training in Nigeria and UK and is presently Head of the Department of Otorhinolaryngology at the University College Hospital, Ibadan.

The Interview was held on 13.12.93 in the Professor's offices at University College Hospital, Ibadan. Due to the noise from the air conditioning unit it was impossible to record this interview. There were numerous interruptions, (more than 30 in an hour!) and it became difficult to direct the information that the Professor wanted to share with me. A summary of the information is recorded below.

The Professor felt that *'The problem'* (that of communication disorders) has to be tackled on three fronts: the Child, the Mother and the Family.

Each group has a number of subgroups and these need different approaches. Children are usually brought to the hospital by urban educated people. *"Most of the parents who come to see me are wealthy, they come with their children because they are important to them, they often have help in the house, they work, they have money, they have transport, but they quickly become impatient, they cannot stay long because they have to go to work."* There is a perception by these people that the solution should be immediate. This makes providing a service very difficult and makes one ask if the service should be provided within a hospital setting?. Parents often give up because they cannot face the long treatment. The solution to this is education. But what kind of education? Conventional education has produced this impatient group who expect immediate solutions.

Children are often brought to the hospital by their grandmothers because the mother is working or has abandoned the child with her parents.

*"Rich people who come to the hospital want an appointment for the child abroad, " they need a letter of referral. They go the UK or USA and then often cannot stay for the follow up overseas which leads to poor results from the treatment.*

*“Educated groups form 75% (of the people) in Lagos,”* but as you move further away the percentage becomes less. The UN says that 35% of Nigerian population is urbanized. There is only a small proportion of people who belong to this group but they are the group who want to use the hospital.

Educated women fight their families who often want the child to be treated in the traditional way, the problem is the mother-in-law!

When people have ‘arrived’ (succeeded) they become philanthropic, in terms of the Muslim faith, a way of paying tithes is to become chairman of a charity.

If a child is ‘subnormal’ he cannot be helped. If there is something they can give, they can give him clothes. *“All disabled are stigmatised people.”*

‘Aribun’ is the Yoruba word for disabled. If there is a disabled child in the family it will reflect in the treatment of all the family. Most people do not want other people to know they have a disabled child. *‘They hide them away ,they are ashamed.’*

The disabled child in a rural area would have more attention and interaction but would be pampered and not disciplined, resulting from pity. The rural area is not the best place for the disabled child to be, because this pity might not prove helpful and the child would not be encouraged to reach his potential.

*“There are another group of parents who feel that the problem is with God.”* On the whole this group never come to hospital. *“They may go to the church for a ‘cure’... ‘the deaf will hear, the lame will walk... This is a cheap option encouraged by church leaders.”*

Inheritance is possible as long as the person is not *‘mentally handicapped’*. Other disabilities do not matter for rank.



*“I have done no operations this year “(1993). We have no water in the hospital so all the patients have been discharged. Teachers have not been paid for the last three months so they cannot be thinking of improving teaching methods, instead they sell food in the market, so that they themselves can eat.*

What action can we take?

- Education through the newspaper, radio and television for the children and mothers .
- Field work through health workers for the community.
- Educate children in schools, educate other children about disability.

**RESUME OF THE INTERVIEW WITH DR. PETER MBA, RETIRED HEAD OF THE SPECIAL EDUCATION DEPARTMENT AT IBADAN UNIVERSITY ON 13.1.94. WITH THE ASSISTANCE OF DR. ALADE, COLLEAGUE AND FRIEND.**

**A transcript of this interview can be found in Appendix 11b.**

Dr. Mba is a graduate of Galludet College in USA, he was deafened post-lingually in childhood due to ototoxic drugs. The interview was conducted on 13.1.94 in his home in Ibadan, using a mixture of speech and sign language and with the help of an interpreter. As a result the communication process was slow and the information gained more repetitive than with the other informants. The conversation was recorded but due to the use of sign and to the very active children and cockerel in the yard the recording was difficult to transcribe! Sections of it were transcribed and can be found in the appendix 11b. A summary of the points made can be found below.

One way of tackling the various problems of a child who cannot communicate is to have input from various professionals but the most important service priority, Dr. Mba felt, was the development of preschool facilities, *“find activities that interest them”* together with family education and involvement. He felt it was important to use family support wherever possible *“I think that families should be involved”* and that programmes should

be developed according to the child's needs. He thought that children learnt to communicate when they could base it on real life experiences and not be exposed to lots of inappropriate 'exercises'. One of the biggest problems in Nigeria was that families were often not interested in helping their child. Getting parents interested and involved was difficult.

The promotion of sign language is very important to deaf people and more attention should be paid to providing teaching in this area, both to deaf people and to hearing people.

There was also a lot of value in enlisting the help of other disabled people, they could help each other, they could complement each other. The '*mentally retarded*' could push wheel chairs for the '*physically disabled*', the physically disabled could speak for the Deaf etc. this could increase self confidence, independence and the feeling of self worth and would be more cost effective.

People need educating. "*It is not enough to educate people in schools they do not attend long enough*" Many families are not interested in '*handicapped*' children, they are rejected by their families. Disabled people are disadvantaged culturally by disability. You can use the media, television and the radio.

There is a great need to change the attitude towards disabled people. "*Changing attitudes is most important. People think disabled cannot do anything good, this needs to be changed but it will take a long time*". "*Disabled people are often seen as a curse from the Gods,*" the family are often ashamed and hide the person or child away from view, they are isolated and treated with caution.

There is a place for "*centres of excellence,*" where people can look for help and more information can be accumulated and developed.

The worst disability is "*mental retardation.*"



## RESUME OF THE INTERVIEW WITH PRINCE PAUL ADELABU, PRINCIPAL OF THE REHABILITATION CENTRE FOR DISABLED, MONIYA ON 11.12.93.

A transcript of this interview can be found in Appendix 11c.

Interviewed on 11.12.93 in the researcher's home. Prince Paul is a dynamic leader of the disabled community both locally, nationally and internationally. He is congenitally physically disabled, born with severely shortened arms and limited digital development. The details of his career are covered in the interview. The interview was recorded and sections of it were transcribed and can be found in appendix 11c. The essential components are reported below:

Prince Paul explains that traditionally in Yoruba Society when a child is born disabled, people believe that the family must have done something wrong to deserve this punishment. Paul and his family had to come to terms with this. The local school rejected him and when the hospital offered to do an operation on his hand his parents refused, they were frightened. The Hospital was a mission hospital and they made his parents sign an oath that they would not kill him. Eventually he was accepted at school because he had taught himself to write and was always top of the class. However, when it came to secondary school he was rejected again, but he went to the Oba of Ilawo (Local Chief) and eventually got in. When he left school, he got a job with the Government in the Treasury Department and eventually got a diploma in local government administration from the University of Ile Ife. Paul went back to his government job and was often asked to talk about disabled people. In 1990 the commissioner of Oyo State asked him if he would be prepared to take over the running of the Rehabilitation Centre at Moniya. It was very neglected at that time, with only a few 'lunatics' being kept there.

He worked to make it a '*participatory project*'. The buildings have been constructed by the Federal Government. The State has contributed as well as Philanthropists. The staff are paid by the government and 10 of the staff are disabled themselves. They have 60 trainees with many different disabilities, who stay one year and then go home and start their own business. They are starting a new programme to help support families when the disabled person returns home as this is a difficult time for them and their families.



Prince Paul feels that the priority for services is to establish good and well run institutions where the government, disabled people, families and the community are involved. *“We need to look after them, give them training and education in schools and institutions”*. Planning of services should involve people at the highest level. If the family is helped to cope they will not run away. Disabled children are *‘dumped’* mainly because the parents just do not know how to cope. Once they have support they will be happy to become involved. The children should go home on holidays and the parents should be encouraged to visit during the term time. Social workers can be used to trace parents and explain their duties to them.

At the same time integrated education where disabled children can attend local school like he did, should be supported. The opportunity to compete with able bodied people is very important, this can give them a positive self image which is very important as disabled people need to be given the opportunity to achieve. Money can be raised, in fact a tax could be levied, say 1% of earnings.

*‘My position and my family are influential and important but I would not have been able to hold this position if I had other handicaps, say for instance mental retardation’* You need to have intelligence and be able to communicate and be respected. The worst handicap is *‘mental retardation’*, *“those who are very hard to handle are the mentally retarded”* this is very hard for the parents and family to handle, but many can learn by example and with patience.

There are very few disabled people in the villages most of them come to the town, maybe they do not survive in the villages. It is better for them to be in the town, there is more stimulation and excitement for them, the village is very dull. The city is better, that is if you can get into an institution or establishment. If you can’t it might be better to be in the rural area, but it is a very hard and dull life. The only way forward in the villages is to identify people who might be able to help the disabled and support them, like a carpenter or something.



The Yoruba believe that disabled people have certain spirits, these can be good or bad. If they are bad the person is rejected, if they are good, the person may be used for worship and seen by other people as a way to approach the Gods, in which case they would pray to them. Either way the person becomes isolated. This doesn't happen so much now, as people are aware of the causes of disability and don't believe this any more.

**5.2.2. ANALYSIS OF DATA GATHERED FROM KEY INFORMANT INTERVIEWS.**

The information gathered in the key informant interviews was analysed by identifying key themes to form the basis of a thematic analysis.

**THEMATIC ANALYSIS OF KEY INFORMANT INTERVIEWS.**

The information gathered in this exercise was subjected to a data reduction process and 10 themes emerged. Two issues were mentioned by all four key informants and can be seen in Table 27, three issues were raised by three of the informants and can be seen in Table 28 and four issues were raised by two of the four informants and can be seen in Table 29. A further four potential themes were suggested by a single informant and are displayed in Table 30.

**Table 27. Two primary themes from key informant analysis.**

Informant	Attitudes towards disability are too negative and need changing	Importance of family and community involvement
ENT Consultant	*	*
Speech Pathologist /Head mistress	*	*
Deaf Educator University Professor	*	*
Phys.Handicapped Director of Centrefor disabled people	*	*

The informants felt that:

- \* There are very negative attitudes towards people who have disabilities (which would include people with communication disorders,) as there are to all types of impairment groups. These attitudes are very disabling. The informants felt that there was a need for these attitudes to be identified and addressed.
- \* These negative attitudes sometimes manifested themselves by the parent’s lack of interest and commitment to helping their child.
- \* The informants felt that it is important to utilise the support and skills of the family and the community in which the disabled person lives, particularly the family, but this may depend on a general education level. One informant felt literacy played a part in the success of sharing this information.

**Table 28. A further three primary themes from key informants.**

Informant	Families not interested	Empowerment	Need for education of and about people with communication disabilities
ENT Consultant	*		*
Sp.Path./ Head mistress	*	*	*
Deafened Educator	*	*	*
Physically disabled Director of Centre for Disabled people		*	

The informants felt:

- \* There is a need to empower the disabled people themselves.
- \* There was difficulty in obtaining and maintaining the interest and enthusiasm of families.
- \* There was a need to educate people with communication disorders, to help them make the most of their abilities and to become useful citizens and not ones that were isolated from society.



\* There is a need to educate people about disability generally. eg about causes of impairments, what disables people, what can be done to help. It is not enough to do this through schools as too great a proportion of people either never attend school or do not attend school for long enough. The informants recommended the use of media, radio, television and drama which can be used to reach the population in need of the information at a time when they need it.

**Table 29. Four secondary themes from key informants.**

A further four issues were considered important by two out of the four key informants as illustrated in the table below:

Informant	Importance of play in early learning	Need revision of structure of system. This should not depend on the government	Consult family about what they want	City based Institutions provide the best service
ENT Consultant				*
Sp. Pathologist /Head Mistress	*	*	*	
Deaf Educator /Univ. Prof.	*		*	
Phys.Impaired Director of Ctr. for dis. people		*		*

The informants felt that:

- \* The importance and value of play is generally underestimated and under used, even by educators. This should be addressed in professional’s training programmes and also in courses and advice to mothers and families.
- \* There is a need to revise the structure of services for people with communication disorders, but people should not rely too much on the government or it will never happen.

- \* It is important to consult the families about what they want, if possible they should be involved in the planning of the whole programme and their ideas used and taken into consideration. They need to be helped to develop their own ideas instead of having everything done for them whether they like it or not.
- \* There were important reasons to develop and maintain city based institutionalised services even though the importance of a rural approach was appreciated. Different emphasis was placed on rural versus city services, the two educators being more inclined to support the importance of rural development and the two more administrative informants seeing the value of centres or institutions.

Table 30. Five additional themes identified by key informants.

Informant	Importance of sign language for deaf people	Traditions are in transition	Important and beneficial to integrate different disabilities	Learning through activity is essential	<i>“Trade training”</i> schemes are important
ENT Consultant					
Sp. Pathologist /Head Mistress		*			
Deaf Educator /Univ. Prof.	*		*	*	
Phys Impaired Director of Ctr. for dis. people					*

Five potential themes were identified, but raised by only one informant. They tended to reflect the key informants particular interests and expertise.

- \* The Deaf educator felt that the teaching of sign language was very important for deaf people and that people who were not deaf should learn sign too so that they could communicate with deaf people.



- \* He felt much could be gained from integrating people with different disabilities, e.g.. the blind with the deaf, he felt this was an underutilised resource and had great empowerment prospects.
- \* He also felt that learning of any kind needed to be activity based, and that this should be reflected in the curriculum of special schools and training of any kind. This comment is perhaps an extension and emphasis of the theme identified in the previous section concerning the importance of play. He talked about the use of drama and physical activities as a way of involving, educating and changing the attitudes of other people in the family and in the community.
- \* The physically disabled Director of the Rehabilitation Centre thought “*Trade Training*” schemes should have a higher profile, as they are a way of empowering disabled people and should not be undervalued just because they did not address everyone’s needs.
- \* The Speech Pathologist felt it was important to appreciate that traditions were in a state of transition, so they were neither ‘*one thing or the other*’. She felt that an awareness of the moving state of attitudes and traditions was important in responding to need and developing appropriate services.

### 5.3.0. GROUP DISCUSSIONS.

The discussions were conducted with four parent groups. The selection criteria and other details are given in the Methodology Chapter, section 4.4.3.

### 5.3.1. RESULTS FROM GROUP DISCUSSIONS.

In Groups 1, 2 and 3. notes were taken of the views expressed, the responses relate to the check list of questions posed for each group to discuss. These questions are printed in bold in the notes taken by the first group and can also be found in Appendix 6. The report of the responses to the questions for each of these three groups are reproduced

below, as they were written by the participants. This is followed by a summary of the main points made by group 4. A full transcript of the group four discussion can be found in Appendix 12.

**Notes taken by group 1.** (6 parents were in this group and it was largely conducted in English. The scribe of this group was one of the parents. They noted the consensus of the group in note form and it is reproduced below.)

“People’s views about questions:

**1. What are your beliefs about children who cannot talk?** One of the parents believes that those handicapped children who cannot talk inherit the problem from their parents. Another parent suggested that to be unable to talk can be due to some kind of disease which affects mothers during pregnancy. At time the cause may not be known. Another cause is the effect of drugs or at time sickness which affect children after birth like measles, jaundice etc.

**2. Do you think people who cannot talk properly should be educated?** Parents agreed that these type of children should be educated so that they do not constitute a nuisance to society and that at times people who cannot talk after receiving special education can talk again with the help of learning aids.

**3. In what way do you treat disabled people differently?** The disabled are sometimes ignored and at times given more attention than other children.

**4. What has helped you most in dealing with your child’s problem?**

The children should be educated and also given more attention at home. We should not ignore them, so they will know they are part of society.

**5. What role should the family/community play in the care of disabled people?** In the family the parents should give them a good education and also other children should not be allowed to look down on them. The community should be able to render help for the disabled one, especially the government. The government needs to provide all the aids needed by the disabled and build more special schools.

**6. How do you feel about your disabled child?** Parents feel bad for having such a child in the family, but with the grace of God we are able to overcome our problems.

**7. How does having him/her in the family affect your daily life?** There are financial problems, transporting him to school, emotional problems.

**8. As parents of children with special needs what do you think they need most?**

- a) Attention
- b) Affection.”



**Notes taken by group 2.**(6 parents were in this group which was conducted mainly in English. The scribe of this group was one of the parents.)

- \* 1. All of us in the group believe they are normal children and should be treated equally. Some believe that it is the work of Satan, some believe it is as a result of illness in pregnancy, drugs or fetish ideas. We all agreed that it is a way of bringing us nearer to God.
- 2. They should be educated and not denied anything.
- 3. Parents should be extra patient.
- 4. God has helped us, like initially some of us felt ashamed displaying them as our children, others do not want friends or relatives to know they have special children.
- 5. The community/family should be enlightened that special people should be given support, special preference and all encouragement they need. They should not be treated as outcasts.
- 6. We all feel happy now about the children, compared to what we felt initially when the problem started.
- 7. Having a special child restricts our movements, social outings, it wastes time and stretches our finances.
- 8. Special children need God, love, care, attention, encouragement, patience, long suffering. Parents should be emotionally strong. We should be positive in thinking about them. We should let them live independent lives."

**Notes taken by group 3.**(9 parents were in this group which was conducted mainly in the Yoruba language. The scribe of this group was one of the teachers who spoke both Yoruba and English.)

"They believe that the child gets his problem from his parents. Hereditary (Amutorun Iba) That the organs, such as the tongue, are not developed. (Eya arako ti dagba to) They may have had measles.  
Expectation: Traditional belief (owo aye) Sickness  
Expectation: (related to the questions posed).

- 1. One day the child will talk. Belief in God that the child will talk.
- 2. They will be able to compete with the other groups in society.
- 3. They give special care in favour of the disabled.
- 4. Special Education Programme has helped the child.
- 5. They should give love and assistance, however the 'love' of the community is very low.
- 6. We used to feel sad but at times they constitute a sort of happiness to us.
- 7. The pace of progress is slow.
- 8. Special attention, special treatment, special interaction."

**Summary of points made by Group 4 's discussion.** (Women with no disabled children. A transcription of most of this discussion can be found in appendix 12)

**Main points made:**

- \* It is God's will that some people are disabled. People should pray and should not interfere with this. (Although its OK for Europeans to interfere)
- \* They appeared to believe strongly in the power of the 'hospital cure'.
- \* The group still held old cultural beliefs about disability, stories that had been handed down to them from their parents and grandparents.
- \* People who were 'crazy' were best avoided.
- \* Disabled people are the responsibility of their families and they should make sure that they are looked after properly.
- \* Did not feel that disabled people could really be 'educated', but special schools were good places for such children to be looked after properly.
- \* It is better for disabled children to stay with their Mother, whether this be rural or urban, if you could choose life in the rural / home area is better for them.
- \* The very best place for disabled people is in Institutions where they can be properly looked after by people who know how to do it, and where they will be fed and protected.

### **5.3.2. ANALYSIS OF DATA GATHERED FROM GROUP DISCUSSIONS.**

The information was reduced and analysed for recurring themes and common views which are represented in the Table 31. but it is important to remember that the number of times an idea is mentioned is only relevant as an indication of the importance of an idea Rifkin (1996) pp28. It gains no more credibility if made into a quantitative measure.



Table 31. Thematic analysis of group discussions.

Identified Themes	Group 1. 6 mothers of CD children (in English)	Group 2 6 mothers of CD children (in English)	Group 3 9 parents of CD children (in Yoruba)	Group 4 6 mothers of 'normal' chd. (in English)
Problem inherited	*		*	
Problem due to disease	*	*	*	*
Problem due to drugs	*			
God's curse		*	*	*
One day the child will talk.	*		*	
Should be part of society treated equally, not ignored or given too much attention.	*	*	*	Did not agree with this
Should be educated	*	*	*	*
Attitude of the community to those who cannot talk is poor	*	*	*	*
Parents should be loving and give assistance		*	*	Demonstrated that it was * Felt this was the parent's responsibility.
Parents feel sad, guilty and responsible. At times children who cannot talk Constitute a sort of happiness or blessing to us.	*	*  *	*  *	*  *
Our children need: Encouragement God support  special attention treatment affection interaction caring.	*  *	* * *  *  *	  * *  *	* *from parents  *  *
These children present practical problems such as restricting movement financial problems.	*	*		
Government should provide special schools.	*			*

**5.4.0. SURVEY 1A.**

To supplement the data collected from the key informants and group discussions a survey of student professional’s knowledge and attitudes about and towards people with communication disorders, was carried out. This survey had two parts. The first part, 1A, required the students to rank the underlying impairment categories related to communication disorders according to severity and the second part, 1B required them to rank the level of disability described by scenarios describing a variety of people with communication disorders.

In Survey 1A, ten related impairment and developmental categories associated with communication disorders were identified using those recorded by Enderby and Philipp(1986). The ten categories used in this study were developed from the 18 listed by Enderby and Philipp, amalgamating some of the lower incidence categories under more general headings such as ‘Voice disorders’ and ‘Degenerative disorders’. See methodology chapter, section 4.4.5. for details.

**5.4.1. RESULTS FROM SURVEY 1A.**

**1A Rank ordering of the related impairment and developmental categories used by Enderby and Philipp (1986) by four student groups in Nigeria .**

The students were asked to rank each impairment / developmental category according to their own perceptions in an order of 1-10, starting with the most severe and ending with the least severe i.e. the lower the ranking number the more severe the perceived disability resulting from the underlying impairment. They were asked to grade them according to the amount of human suffering they were likely to experience and the effect that this might have on their family and friends. The results for the four sub-groups are shown in Table 32 and for the group as a whole in Table 33.



**Table 32.**  
**Ranking of the perceived severity of related impairment and developmental groups associated with communication disorders. Scores for each of the four groups of students.**

	Four Sub-groups with a total of 63 subjects Average value or mean of ranking scores (median shown in brackets)			
Impairment and developmental groups related to communication disorders	Student Nurses 20 subjects	Special Ed. students. 20 subjects	Disabled Special Ed. students 10 subjects	Agricultural students 13 subjects
Head Injury	2.350 (2.0)	3.300 (3.0)	3.300 (3.5)	2.308 (2.0)
Mental Handicap	3.150 (4.0)	3.050 (2.5)	2.800 (2.0)	2.308 (2.0)
Cerebral Palsy	2.650 (2.0)	3.100 (2.5)	3.000 (2.5)	3.846 (3.0)
Degen. Diseases	4.100 (3.0)	3.400 (2.5)	3.900 (3.5)	3.385 (3.0)
Deaf	5.900 (5.5)	5.350 (3.0)	6.200 (5.5)	6.385 (7.0)
Cleft Palate	7.450 (8.0)	6.750 (5.5)	6.500 (6.0)	7.154 (8.0)
Voice disorders	6.950 (7.0)	7.250 (6.5)	5.900 (6.5)	7.615 (8.0)
Pre-school child with Speech and Lang. disorder	7.000 (6.5)	7.250 (7.5)	8.400 (8.5)	6.000 (6.0)
School child with speech and Lang. disorder	6.950 (7.0)	7.850 (9.0)	8.600 (8.5)	7.231 (8.0)
Stammer	9.000 (9.0)	7.700 (8.0)	6.800 (7.5)	8.769 (9.0)

In Table 32, both the mean and the median scores are displayed, the median scores are shown in brackets. The researcher appreciates that using the median scores would be more sensitive to the range and lack of uniformity represented in the ranking procedure but has ranked the scores according to the mean, as the decimal points enable demarcation between the ranking. Observations of the differences between the mean and the median rankings highlight the difference between the teachers’ observations of the mentally handicapped as less severe than the other groups, while Agricultural students observed deaf people as less disabled than the other three student groups. The small size of the samples limited meaningful statistical analysis of the differences between the groups.

**Table 33. Rank order of severity by mean of all groups together.**

	Causes	Mean	Standard deviation
1.	Head injury	2.79	1.89
2.	Mental Handicap	2.89	1.98
3.	Cerebral Palsy	3.10	1.91
4.	Degenerative disorders	3.70	2.33
5.	Deaf	5.87	1.86
6.	Cleft Palate	7.02	1.96
7.	Voice	7.02	2.05
8.	Pre-school	7.10	2.39
9.	School child	7.56	1.98
10.	Stammer	8.19	1.79

**5.4.2. ANALYSIS OF DATA FROM SURVEY 1A.**

Young educated Nigerians had no problem with ranking the causes of communication disorders according to their perception of the severity and all student groups displayed knowledge and opinions about the consequences of illness and the resulting disability.

The results supported the perception that people with communication disorders were seen as disabled people, but it did not give information about how much of the perception of disability was due to the observed underlying cause, such as their learning disability, and how much was due to the perception of the inability to communicate. The etiologies which were more focused towards, or related directly to, communication disorders, e.g. deafness, cleft palate, voice disorders and stammering, together with those disorders which do not have obvious etiological explanations, produced the groups which were considered to be less disabled. This would indicate, somewhat understandably, that the more global disabilities are considered to be more severe.

There was close agreement among the groups as to the severity of different disabilities.

People with head injuries, cerebral palsy and mental handicap were considered to be more severely disabled than the other groups and according to Enderby and Philipp (1986), a



large proportion of these groups, 20%, 60% and 55% respectively, are estimated to have communication disorders.

Qualitative observations on the responses in this section:

1. The widest spread of response was found in the school children and the pre-school group, this may have been due to a lack of clarity and the less specific nature of the description.
2. The other two areas with a wide spread of response were cleft palate and deafness. It is possible that the students had very little first hand knowledge of people with these disorders.
3. The Nurses as a group showed greater homogeneity in their ratings than any other group. Perhaps this reflected the less flexible and scientific nature of their training, resulting in greater conformities?
4. The widest range of response came from the Agricultural students which might be expected from a group with a wider age range from different countries and may also be indicative of the transition they were making from completely old traditional approaches and attitudes, to responses based more on western knowledge and perceptions.
5. The Deaf students completing the questionnaire, considered the disability of deafness to be milder than other handicaps.

5.5.0. SURVEY 1B

5.5.1. RESULTS OF SURVEY 1B .

Significant p-values, using  $p < .05$  as the level of significance are marked with\*\* those approaching significance,  $0.05 < p < 0.1$  are marked with \*. The Kruskal- Wallis one- way analysis of variance and the Bartletts test of homogeneity of variance are used because this is non-parametric data.

Table 34.  
Scores of 20 scenarios by four groups showing median scores and P-values between all groups using Kruskal-Wallis and Bartlett

Scenarios	Nurses	Teachers	Dis.Teachers	Agric.	Kruskall-Wallis	Bartlett
1	4	5	4	5	0.3747	0.005 **
2	3	3	3.5	3	0.9105	0.9105
3	3.5	4	2.5	4	0.0224 **	0.5268
4	2	2	1	2	0.9039	0.5866
5	2	3	2	2	0.7105	0.8013
6	2	3	1.5	3	0.3234	0.1678
7	3.5	3	4	4	0.2751	0.3696
8	2	3	3	3	0.0707 *	0.4743
9	3	4	2.5	3	0.2048	0.3896
10	2	3	3.5	2	0.4671	0.9767
11	4	5	4	4	0.6532	0.012 **
12	3	2	2	2	0.0954 *	0.8816
13	3.5	3	3	3	0.5	0.8026
14	3	2	3	3	0.8965	0.1394
15	4	3	3	3	0.146	0.389
16	3.5	3.5	3	3	0.4395	0.6184
17	5	5	5	5	0.8702	0.00008 **
18	3	3	4	2	0.5411	0.536
19	3	3	3	2	0.3123	0.4828
20	3.5	3.5	3.5	3	0.5927	0.8232

INITIAL ANALYSIS OF DATA GATHERED FROM SURVEY 1B.

Analysis used Bartletts and Kruskal-Wallis tests and intends that the information they reflect should be read together. The Bartlett reflects p-values in similarity, the Kruskal-Wallis in difference. In Table 34 it can be seen that the Bartlett test shows that the response from the groups to three scenarios are significantly similar, leaving 17 which are different, of these 17 only one is significantly different and two others are approaching significance. The Kruskal-Wallis shows one scenario (No.3) where there is a significant difference between the responses of the groups, and two scenarios (Nos. 8 and 12) where the difference between the groups is approaching significance. The residual scenarios are considered to be the same. Bartlett’s test for the



homogeneity of variance identifies three of the residual scenarios (Nos. 1, 11 & 17) as significantly similar. These scenarios are discussed later in this section but the overall conclusion from this data is that there is no significant difference or similarity between the groups' responses to the scenarios. Only in scenario number 3 did the p-value indicate that the different response from the groups might not be due to chance. The group that showed the greatest difference in their response to this scenario were the disabled teachers. The scenario was about a 40 year old man who had a stroke and as a result could not understand what was said to him. The disabled teachers felt this was much ~~less~~ disabling than the other groups, showing evidence of an empathy with the man's difficulties that non-disabled people found more difficult to identify.

The other two scenarios that showed a p-value approaching significance were scenarios 8 and 12. In both these scenarios it was the nurses who were the group that differed from the rest. Scenario 8 was about a 10 year old cerebral palsied girl who stayed at home who although she understood what was said to her could only talk very slowly and indistinctly herself. The nurses found this girl less disabled than the other groups perhaps because of the chronic rather than acute nature of her disability or the other groups may have known similar cases and been more familiar with the difficulties this disability might create in the running of the home or school. Scenario number 12 was about a three year old boy who was not talking at all but understood what was said to him. In this case the nurses found him more disabled than all the other groups, perhaps because they may have had experience of such cases in children's wards in hospitals with more serious underlying causes than children in the home and community whose speech development was delayed and who made spontaneous progress at a later age.

Bartlett's test of homogeneity of variance shows that in scenarios 1, 11 and 17 the similarity of the groups is greater than could be expected by chance. All three scenarios describe people with severe disabilities. In scenario 17 all the groups show the same median value showing that they all considered an 18 year old man with cerebral palsy who could not walk or talk and sat at home all day, to be severely disabled. Scenario 1 was about a 3 year old mentally handicapped boy who had no understanding or communication, even with his family and scenario 11 was a 14 year old girl with a head injury from a car accident leaving her without coherent speech or understanding. It would seem that for these 3 scenarios describing severe levels of disability there is significant agreement among the groups.



5.5.3. FURTHER ANALYSIS OF RESULTS OF SURVEY 1B.

In the light of the limited information gained from the initial analysis it was decided to re-group the data to observe the contrast, if any, between differently grouped sets of respondents. As a result of the initial analysis showing that in three of the questions the nurses showed a significantly different or almost significantly different response, it was decided to re-group the data to see if as a group the nurses were different from the rest of the students put together, this analysis is shown in Table 35. An analysis was also made of a re-grouping of the disabled group against the other three groups. This analysis is shown in Table 36.

Table 35. Mean ranking of 20 scenarios between group 1 (nurses) and the other three groups. The standard deviation is shown in brackets() median shown in [].

Scenario	Gr.2,3,4	Gr.1.	Mean diff	Bartlett	K-Wallis
1	4.140 (1.082) [4]	4.150 (0.489) [4]	-0.01	0.0004 **	0.403
2	3.000 (0.976) [3]	3.050 (0.826) [3]	-0.05	0.4075	0.882
3	3.558 (1.278) [4]	3.350 (1.040) [3]	0.208	0.3102	0.275
4	1.814 (0.982) [2]	2.050 (1.191) [2]	-0.236	0.3183	0.541
5	2.233 (1.192) [2]	1.950 (0.999) [2]	0.283	0.3816	0.303
6	2.744 (1.432) [3]	2.350 (0.933) [2]	0.34	0.0416 **	0.269
7	3.093 (1.461) [3]	3.150 (1.182) [3.5]	-0.057	0.2977	0.969
8	2.628 (1.092) [3]	1.950 (1.050) [2]	0.0.678	0.845	0.024 **
9	2.907 (1.360) [3]	2.500 (1.000) [3]	0.407	0.1365	0.138
10	2.698 (1.597) [3]	2.400 (1.501) [2]	0.298	0.7559	0.412
11	4.163 (1.111) [4]	4.300 (0.571) [4]	-0.137	0.0023 **	0.79
12	2.140 (1.265) [2]	2.900 (1.071) [3]	-0.76	0.411	0.21 **
13	2.884 (1.219) [3]	3.250 (1.118) [3]	-0.366	0.6648	0.239
14	2.488 (1.404) [3]	2.400 (0.883) [3]	0.088	0.0283 **	0.772
15	2.907 (1.231) [3]	3.350 (0.875) [4]	-0.443	0.1	0.096 *
16	2.953 (1.379) [3]	3.350 (1.137) [3.5]	-0.397	0.3399	0.348
17	4.442 (1.181) [5]	4.550 (0.605) [5]	-0.108	0.0022 **	0.58
18	2.837 (1.463) [3]	3.050 (1.395) [3]	-0.213	0.8101	0.647
19	2.860 (1.167) [3]	2.558 (1.356) [3]	0.31	0.4376	0.38
20	2.860 (1.656) [3]	3.350 (1.387) [3]	-0.49	0.3809	0.312

Significant p-values, using  $p < .05$  as the level of significance are marked with\*\* those approaching significance,  $0.05 < p < 0.1$  are marked with \*. The Kruskal- Wallis one-way analysis of variance and the Bartlett's test of homogeneity of variance are used because this is non-parametric data.



Table 35 shows that the mean differences were negative in 12 of the 20 scenarios indicating that the nurses perceive people as more disabled than the other groups in 12 out of the 20 scenarios, but given the small sample size this would appear to be very little above what could be expected by chance and is one scenarios less than the negative responses of the disabled students.

In scenarios 1,6,11,14, and 17 Bartlett's test indicates that the nurses are responding in a significantly similar way to the rest of the students, although as we have seen in the initial analysis, in scenarios 8 and 12 it was the nurses as a group, which differed from the rest. This difference can be seen a second time in the subsequent analysis with the Kruskal-Wallis showing significant differences for these two scenarios. However in the light of this second analysis it would be incorrect to conclude that the results show a **significantly** different response, however this may be due to the small sample size and it must be remembered that taking Bartlett's results, 5 of the scenarios showed a similarity leaving 15 that were in some way different. A larger sample might provide the material to display this difference. Only in 8 and 12 were significant differences to be found.

Observation of the smaller standard deviation shown by the nurses as a group in comparison with the other groups, in 18 out of the 20 scenarios, supports the researchers observation that the nurses were more homogenous in their responses to the scenarios.

**Table 36.**  
**Mean ranking of 20 scenarios between the disabled student group and the other three groups. Median scores shown in brackets.**

Question	Grps1,2&4	Grp 3	Mean diff	Bartlett	Kruskal-Wallis
1	4.226 (4)	3.7 (4)	0.526	0.0126 **	0.228
2	2.981 (3)	3.2 (3.5)	-0.219	0.9631	0.486
3	3.66 (4)	2.6 (2.5)	1.06	0.4277	0.019 **
4	1.887 (2)	1.9 (1)	-0.013	0.553	0.82
5	2.13 (2)	2.2 (2)	-0.068	0.733	0.815
6	2.679 (3)	2.3 (1.5)	0.379	0.251	0.302
7	2.981 (3)	3.8 (4)	-0.819	0.138	0.093 *
8	2.302 (3)	3 (3)	-0.698	0.239	0.06 *
9	2.811 (3)	2.6 (2.5)	0.211	0.92	0.635
10	2.509 (3)	3.1 (3)	-0.591	0.117	0.274
11	4.264 (4)	3.9 (4)	0.364	0.288	0.394
12	2.415 (3)	2.2 (2)	0.215	0.919	0.574
13	2.981 (3)	3.1 (3)	-0.119	0.99	0.913
14	2.415 (3)	2.7 (3)	-0.285	0.18	0.467
15	2.962 (3)	3.5 (3)	-0.538	0.859	0.294
16	3.038 (3)	3.3 (3)	0.262	0.367	0.676
17	4.453 (5)	4.6 (5)	-0.147	0.0146 **	0.8029
18	2.811 (3)	3.4 (4)	-0.587	0.13	0.281
19	2.679 (3)	3.2 (30	-0.521	0.095 *	0.156
20	2.962 (3)	3.3 (3.5)	-0.338	0.787	0.59

Significant p-values, using  $p < .05$  as the level of significance are marked with\*\* those approaching significance,  $0.05 < p < 0.1$  are marked with \*. The Kruskal- Wallis one- way analysis of variance and the Bartletts test of homogeneity of variance are used because this is non-parametric data.

Group 1-Nurses, Group 2 -Teachers, Group 3-Disabled Teachers,  
Group 4 - Agriculturalists.

Bartlett’s test showed a significant similarity in the responses to two of the scenarios, leaving 18 that were different. Of this 18 one was close to significance leaving 17 making the responses of the disabled group more different than the nurses responses. Only in scenario 3 was there a significant difference between the response of the disabled student teachers and the other student groups. This scenario related to a 40 year old man with a stroke and the disabled students observed him as less disabled than the other student

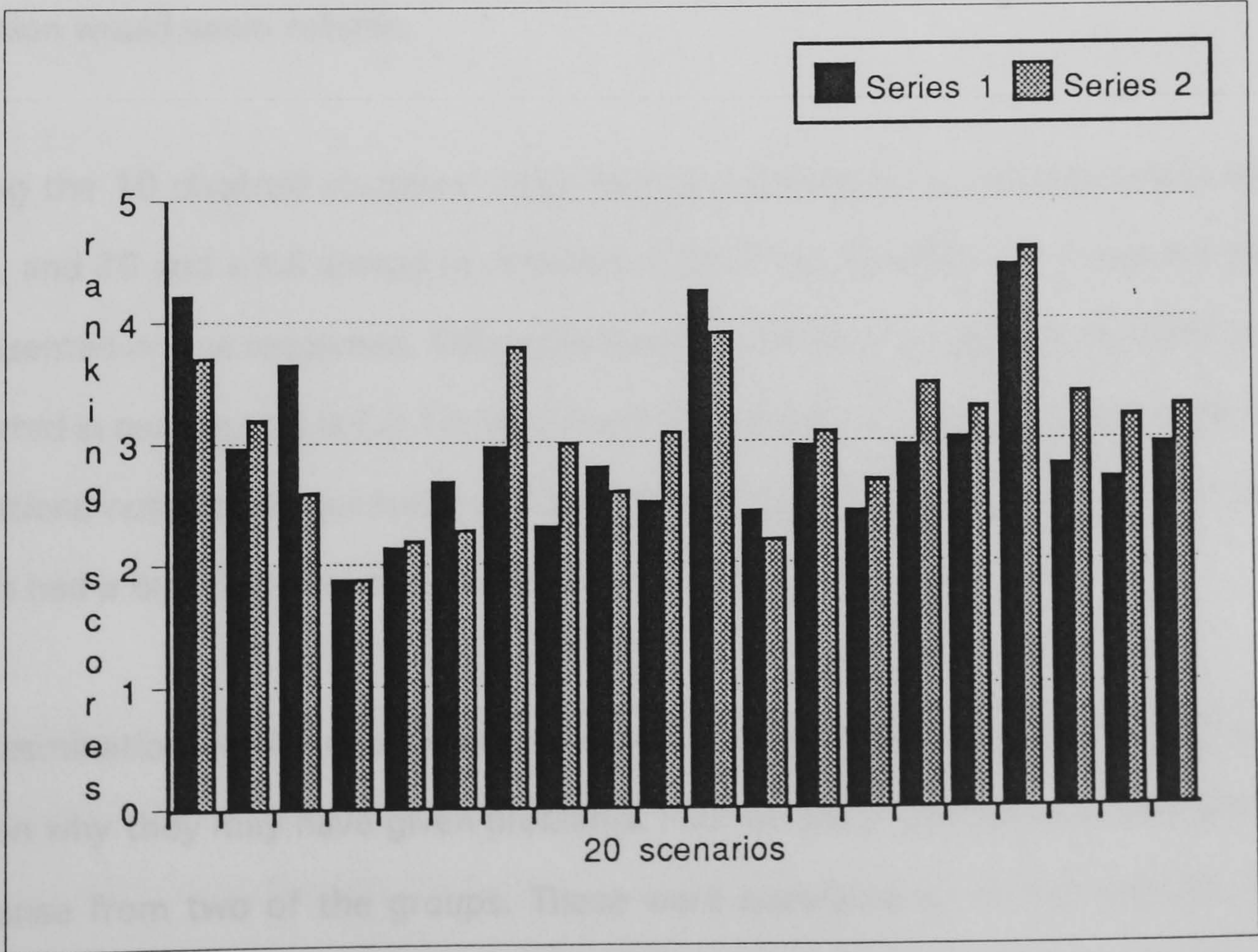


groups, whereas their responses to scenarios 7 and 8 were approaching a significant negative difference to the other groups, the disabled students found the six year old boy who was starting school with unclear speech and the 10 year old cerebral palsied girl who spoke slowly but could understand what was said to her, as ~~more~~ disabled than the other students. These observations may show evidence of a greater understanding of the realities of disability.

Only scenarios 1 and 17 did the Bartlett show significant similarity between the responses of the student groups. These scenarios, as discussed previously, described people who were considered by most to be more severely disabled.

The mean differences between the groups were negative in 13 out of the 20 questions, see Figure 6, one more than the nurses, indicating that the disabled group observed the people described in the scenarios as more disabled than the other three groups, even though the differences between these observations were not to a level of any significance. The proportion is not however very much greater than that expected by chance, (i.e. 50%).

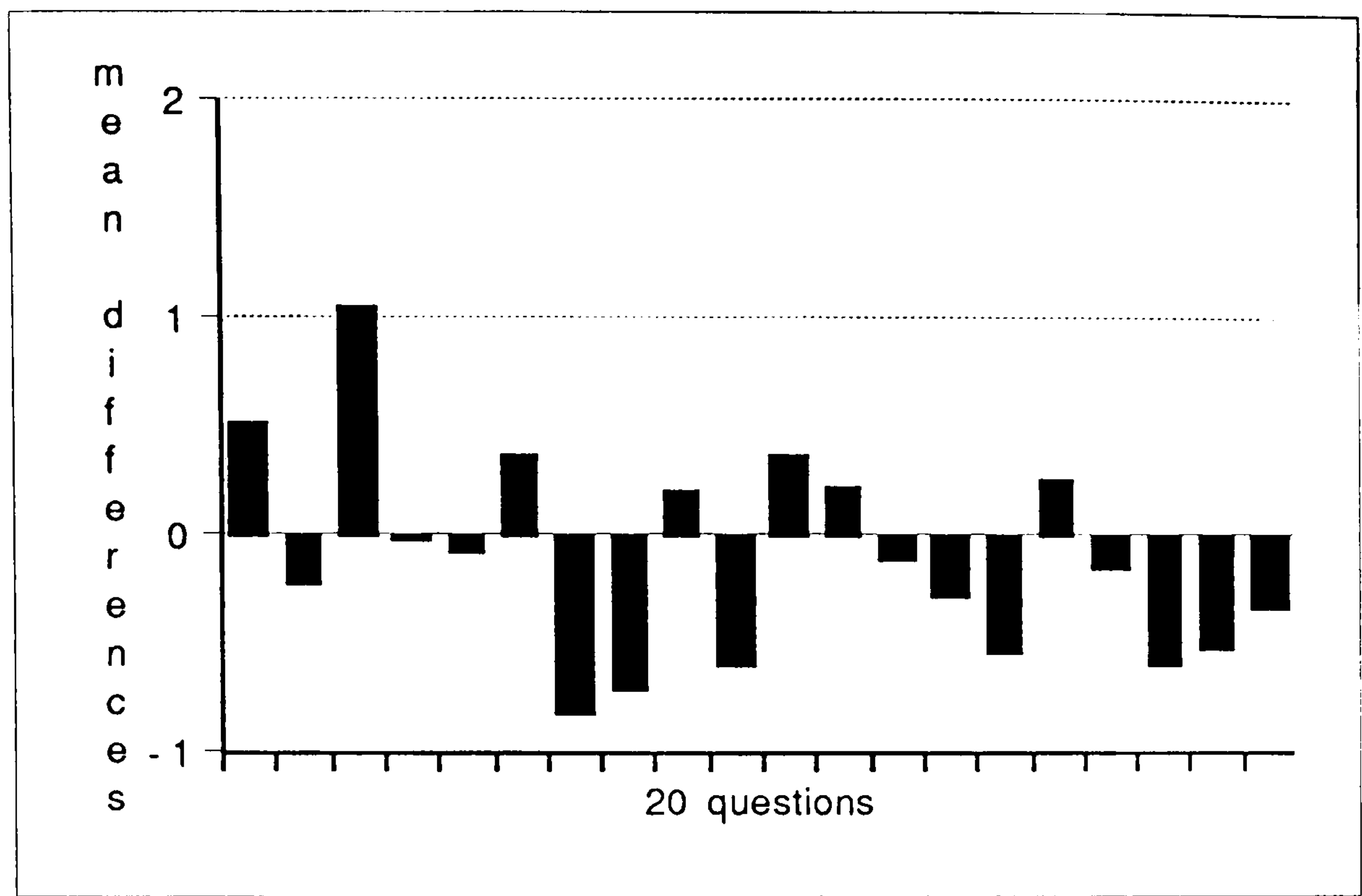
**Figure 5.** Bar chart showing that the disabled group perceived people as more disabled than the other three groups in 13 out of the 20 scenarios.



**Series 1-** Groups 1,2,4 - Able-bodied students **Series 2-** Groups 3 - Disabled students.



Figure 6. Mean difference between the disabled students and the other students showing the negative differences in 13/20 of the scenarios presented.



#### 5.5.4. QUALITATIVE ANALYSIS OF THE RELIABILITY OF QUESTIONS.

To make some assessment of the reliability of the questions, it was decided to look at the agreement that occurred on the individual questions. The assumption here is that if there is general agreement about the degree of severity of the disorder described, then the question would seem reliable.

Taking the 10 disabled students, large standard deviations were observed in questions 9,14, and 20 and a full spread of response from 0 (no disability) to 5 (severe disability) represented in their responses. Taking the Special Education Group large standard deviations occurred in questions 3,6,7,9,14,16,18 and 20. Taking the Student Nurses large standard deviations occurred in questions 4,10,13,18 and 19. This gives a total of 12 questions which had a broad spread of response.

On examination of the questions concerned it was not always possible to predict the reason why they may have given problems. Four of the questions showed a wide spread response from two of the groups. These were questions 9, 14, 18 and 20. They are considered in more detail.



**Question 9.**

A possible explanation for the difficulty with this question is the relatively small number of Laryngectomy operations which are likely to be performed in the country, and therefore the chances of first hand experience with this disorder are slight.

**Question 14.**

Stammering appears to be relatively common in Nigeria judging by the number of cases presenting to the University speech and hearing clinic. Also the practice of standing up to read to the class would seem to be practised much more often in Nigeria than in England. I cannot think of an explanation for the difficulty with this question.

**Question 18.**

Perhaps the difficulty arises with this question because there is no obvious etiology represented in this case and this creates confusion. Some may consider the difficulty severe because of the frustration caused by the lack of understanding, while others may not view it seriously because of the lack of obvious etiology.

**Question 20.**

The complexity of this disorder may be difficult to grasp, such children would probably be considered a little slow and perhaps, as a 12 year old girl, more likely to be asked to help at home. However many of the students answering the questionnaire may identify with this problem even if their difficulties were only related to second language learning. Doing badly at school may not be viewed as a disability as many children do not go to school at all, on the other hand achieving at school would appear to have greater influence and effect on that individual's access to jobs and money.

The diversity of the responses given to such a large proportion of the questions, may in some part be due to the widely different perceptions of disability found in Nigeria, and not entirely to the structuring and content of the questions themselves . It also serves to emphasize the complexities of these difficulties.

In Nigeria additional factors need to be taken into account such as:

- the effect of the combination of traditional beliefs and scientific knowledge in a stage of transition.
- greater level of tolerance towards disasters generally.
- greater ability to observe and be thankful for what you have got.
- less inclination to hanker after what may seem unattainable.
- no concept that people have a “right” to education or health care.

#### **5.5.5. SUMMARY OF ANALYSIS OF DATA COLLECTED FROM SURVEY 1 B**

- \* Analysis of data collected in Survey 1B showed that all groups could do the task but there was no statistically significant difference among the four student groups . Seventeen of the twenty scenarios presented, showed p values of between 0.1394 - 0.976, six < .08, giving a clear indication that the null hypothesis (that the median of each of the groups are the same) was correct. See Table 34.
- \* Closer examination of the data for trends, revealed that the three scenarios that had responses showing a significant p value for the Bartlett Q1.  $p = 0.005$  Qu. 11.  $p = 0.0012$  and Qu. 17.  $p = 0.00078$ . provided some evidence, that the similarity of the responses was not to be due to chance. These scenarios described people suffering from very severe communication disabilities. There seemed to be greater agreement achieved the greater the severity of disability observed.
- \* Smaller standard deviations of response indicated that the nurses were more homogeneous in their observations.
- \* Higher levels of negative mean differences support the idea that disabled students and the nurses saw people as more disabled than the other groups. The fact that these differences show at all given the small sample size, would indicate that further study with larger groups may show a more significant response.



5.6.0. SURVEY 2.

Parents or close relatives of 21 children out of a potential of 38 filled in the questionnaire at the school after a parents meeting. Another five parents submitted the forms to the secretary a few days later. They had been unable to attend the meeting but wanted their forms to be included in the survey. This made a total of 26 responses.

5.6.1. RESULTS OF SURVEY 2.

The numbers quoted are out of a total of 26 unless otherwise stated.

- 1. 21 (80%) of parents attending the meeting were Mothers.  
4 (15%) of parents attending the meeting were Fathers.  
1 (5%) of the adults attending the meeting were sisters.
- 2. 18 (69%) of the children had been suffering from a communication disorder for more than five years.
- 3. In response to the question ‘Where have you taken your child for help?’ the responses were as follows:

School	26 (100%)
Hospital	24 (92%)
Health Centre	13 (50%)
Traditional Healer	7 (26%)

4. In response to the question ‘How many times have you attended each Centre?’

All cases had attended the School more than 5 times and the other Centres had been visited as follows:

	Health Centre	Hospital	Trad. Healer
More than 5 times	5	11	1
5 times	3	4	1
4 times	1	1	0
3 times	2	3	0
2 times	2	2	1
once	1	1	-
No response	-	2	4
Total responses	14	22	3

11 (42%) of the children had been to the hospital more than 5 times.

It can be seen that the least visits were made to the Traditional Healer.

5. In response to ‘How far do they travel to these services?’

	Health Centre	Hospital	Trad. Healer	School
Under 5 km	5	6		6
5-10 km	3	10	1	12
10-50 km		1		4
50 km		4	3	
No response	6	3	4	4

Only 7 (26%) of the children had travelled more than 50km to the Health Centre, Hospital, Traditional Healer, or School.



6. In response to ‘What transport did they use?’

	Health Centre	Hospital	Trad. Healer	School
Walk	1			
Bike				
Bus		2		1
Taxi	1	6	2	5
Car	6	11	2	12
Own car	3	5	3	5
No response	2			4
Total number	13	24	7	26

Only 1 (3.8%) walked to the Health Centre Hospital Traditional Healer or School and 22 (85%) went to school by car or taxi.

7. In response to ‘What is the cost of transport?’

	Health Centre	Hospital	Trad. Healer	School
Nothing	3	2		2
Under 5N	2	5	1	5
10-20N	1	8	1	12
50-100N		3		
More	4	4	3	4

24 (84 %) of parents paid 10-20 Naira for transport to the various centres which they had attended (i.e. between 25-50p, given the exchange rates at the time).

8. In response to ‘Who did they see?’

	Doc	Nurse	HW	Ther	Spiritualist	Healer	Herb	H/teach	Teach	Specialist
HC	9	2								
Hosp.	21	6	3	10						
Tr. H.					3	3				
Sch								19	11	3

21 (80%) of cases who visited a hospital saw a doctor

19 (73%) of all cases saw the head teacher.

10 (38%)of cases visiting the hospital saw a therapist.

9. In response to ‘What did it cost per session?’

	less 10	50N	100N	200N	500N	Total cost
HC	3	1	2	1		480N
Hosp.	1	3	1	4	9	5,560N
Tr. H				2	1	900N
Sch.				1	23	11,700N

Approximate total costs of the whole group are given in the last column and it can be seen that most money had been spent on schooling, in fact 23(88%) paid more money for schooling than other forms of help.

10. In response to ‘What kind of help did you receive?’

	Advice	Medicine	Therapy	Operation	Onward	Riituals	Teach	Specialist	Other
H/C	9	1							
Hosp.	13	9	7		1				
Tr/H	1	2							1
School	9						23	2	



11. 12/25 (46%) were given medicine to help make their child talk better.  
13/25 (54%) had not been given medicine.

12. 13 (50%) of parents had given the medicine more than 10 times.

13. In response to ‘Was it helpful?’

	Rating 0	Rating 1	Rating 2	Rating 3	Rating 4	Rating 5
HC	20	2	1			1
Hosp	8	7	2	2		5
Trad. Healer	21	1	1	1		
School	2		1		2	19

The parents rated the School as the most helpful and the Traditional Healer as the least helpful. This perhaps because they completed the questionnaire in the school and many of them did not appear to have consulted the Traditional Healer at all. The Health Centre was also rated very poorly.

14. None of the parents could name the medicine that was used .

15. Which of these services did you go to first?

	1st	2nd	3rd	4th
Health Centre	7	4	1	0
Hospital	13	8	2	1
Trad Healer	1	3	2	0
School	3	7	11	3

13 (50%) went to hospital first.  
14 (53%) went to school as a 3rd or 4th option.

16. In response to ‘Who else helps?’

Grandmother	3
Auntie	0
Brother/Sister	10
Friend	2
House help	2
No one	10

10 (38%) of parents recognised the help of their other children in looking after their disabled child and an equal percentage, 10 (38%), felt they received no help from anyone.

17. and 20. In response to ‘What are the wants and needs?’ and ‘What can be done to make his/her life better?’

Many parents only answered one of these questions, or their responses were the same to both. It was therefore decided to amalgamate the Information gathered from the answers to these two questions.

Good education	14
Special Attention	8
More attention	9
Extra Love	7
Encouragement	2
Extra Time	2
Family support	1
Talking/Interating with them	3
More money	1
Watch TV	1



Taking ‘special attention’, ‘more attention’, ‘encouragement’ and ‘extra time’ all as examples of more attention, 81% of parents considered that their children needed more attention of some kind.

14 (53%) of parents considered a good education as an important need.

7 (27%) of parents thought their children needed extra love.

18. Does the community help you look after your child?

10 parents (38.5%) felt the community provided help.

15 parents (58%) felt the community did not help.

1 parent (3.8%) did not respond.

19. What will happen to your child and how can you make his/her life better?

Become independent	13
In God's hands	7
Stay at home	6
Become literate	3
Become an artist	1

Half of the parents (50%) felt that their child would/should eventually become independent.

### 5.6.2 ANALYSIS OF DATA COLLECTED FROM SURVEY 2.

1. The high proportion of Mothers completing the questionnaire indicated that they were more involved/interested in the care of their communication disabled children than other members of the family (and it is to them that support should be given.)
2. Communication disorders tend to be chronic in nature and as such are not likely to respond or benefit from short term interventions. It indicates that their needs are long term and on going.
3. It would seem that people turn to the medical services first for help (92% of the children in question had been taken to a hospital first) and that the knowledge and expertise required to help them at this initial first stage is lacking (they were disappointed with the help they received from them). These two points have implications for training medical workers, particularly doctors, and making sure they have the knowledge required to give to the families that seek help or at least send them to people who can help them.
4. The greatest number of visits were made to the hospital and the least to the Traditional Healer. This result did not support observations made during participatory observation, nor information in the literature Landsowne (1991), which indicates that many people consult the traditional healer. The researcher wondered if perhaps the parents felt they might offend the researcher by responding positively to this question.
5. Children did not travel far to school or hospital. The children who attended this school seemed to live locally. It is unclear if this was intentional or if a similar school set up in another district of Ibadan would draw the same number of pupils with communication disorders
6. The majority of children (84%) were from wealthy enough homes to have their own car or afford a taxi.



7. Again the majority of children 84% paid for their transport, indicating a level of wealth.
8. The majority of children saw a doctor at some stage, however 41% of the children taken to the hospital had also seen a therapist. This is a surprisingly high proportion of children who have seen a therapist of some kind. This may be due to the confusion which arises about who is a therapist and who is a doctor.
9. More money was spent on Education than on any other kind of help. Again this is not surprising as the school offers the only long term and ongoing service which appears to meet an identified need. Also this questionnaire was filled in solely by people whose children were attending the school.
10. The most common 'help' other than 'teaching' is 'advice'.
11. Prescribing medicine to cure communication disabilities happens in nearly half of the cases. Details about what form this took were not forthcoming.
12. The majority of parents felt that School was the most helpful service. Again this is likely to be the case as the respondents' children all attended the school and also it offered on-going support where none other was available.
13. Most parents took children to the hospital first.
14. Apart from parents, brothers and sisters take on the biggest role of caring for children with communication disabilities. There was generally a lack of support for the family. This has implications for education and support services.
17. Special attention, more attention, extra time and encouragement were observed as the greatest want/need of children with communication disorders. A good education also ranked high on the priority list. There was a recognised need for love and affection.

These expressed needs could form the basis for discussion and a plan of action in self help groups. These groups could work towards responding to the parents' expressed needs by developing self help and support groups to organise more time and attention for the children, at the same time as empowering the parents to meet some of the identified needs themselves, rather than always turning to the school and its staff.

#### **5.7.0. SURVEY 3.**

##### **5.7.1. RESULTS FROM SURVEY 3. COMPLETED BY COMMUNITY DEVELOPMENT ASSISTANTS (CDAs) IN UGANDA.**

1091 questionnaires were completed in total over a two month period by 57 community development workers.

50 questionnaires were discarded because:

- 16 gave incomplete data

- 7 were for children under 1 year

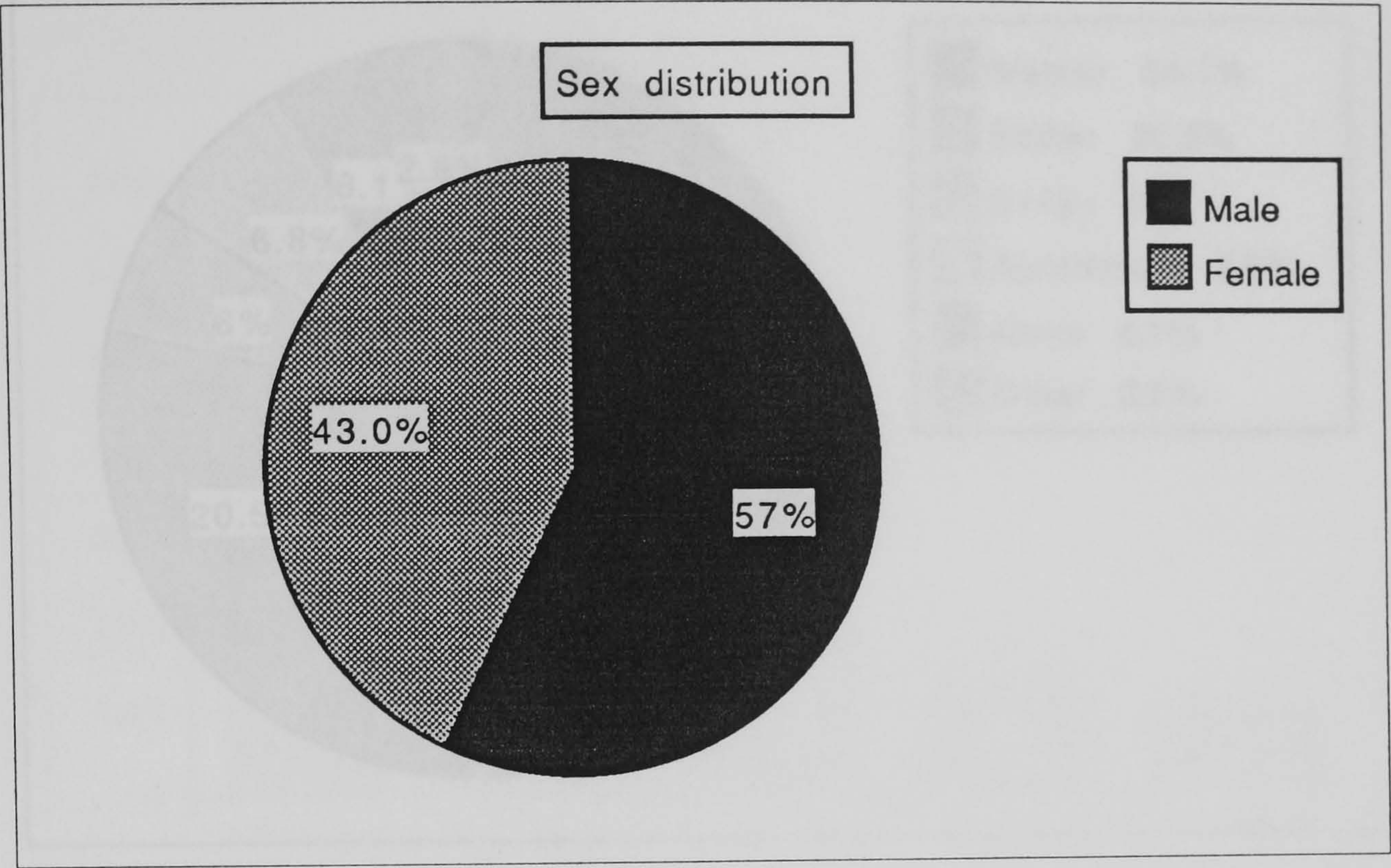
- 22 were completed outside the agreed time period.

Therefore 1041 questionnaires were successfully completed and used as a basis for data entry and analysis.

Sex distribution of the sample is shown in Figure 7.



Figure 7. Sex distribution of the children presenting to CDAs during the two month period.



Of the 1041 questionnaires 363 were completed in the Iganga area.

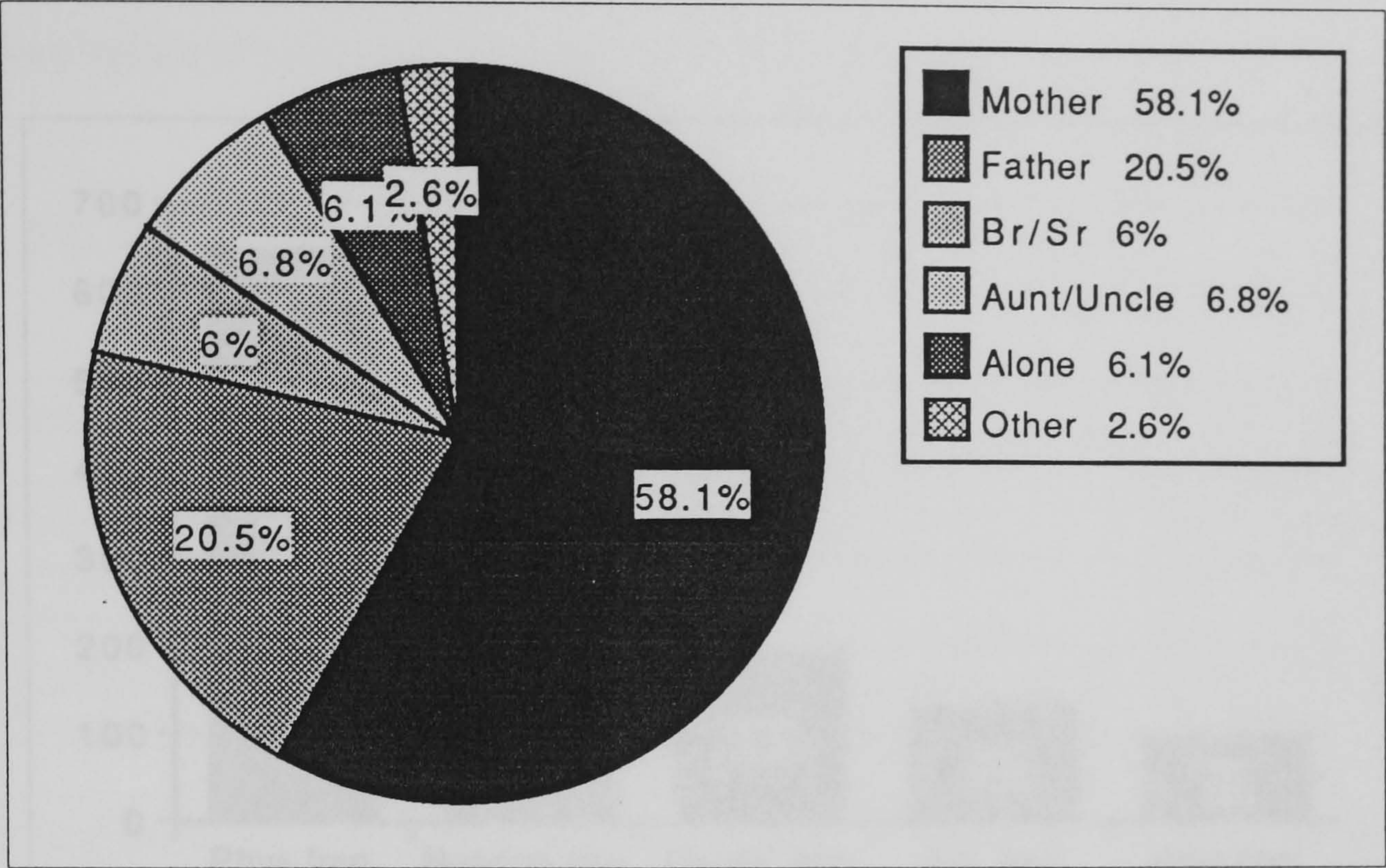
The CDA's observations concerning 304 in the Mbale area.

are displayed in Figure 9. 374 in the Tororo area.

Breakdown of who brought the children to the CDAs for help is shown in Figure 8. It can be seen that the majority, 58%, of the children were brought by their Mothers.



Figure 8. Who brought the 1041 children to the CDAs for help?



The CDA’s observations concerning the overall impairment categories of the 1041 children are displayed in Figure 9. It can be seen that physical impairment is the largest category, hearing, mental, visual and emotional impairment occurring in descending order. Analysis of impairment breakdown in the three areas of Iganga, Tororo, and Mbale showed a similar pattern overall. One slight difference in the Iganga data showed mental impairment being more prevalent than hearing impairment. (Note that some cases, 21.1%, had multiple impairments the overall numbers therefore exceed 1041.)

An alternative breakdown of the same data is presented in Figure 10. showing the number of children presenting with a communication disability. This is defined by one or more negative responses to the 10 questions posed, whether that response be observed or reported. Using these criteria 49.1% of the children have a communication disability.



Figure 9. Children identified according to their impairment group by the CDAs.

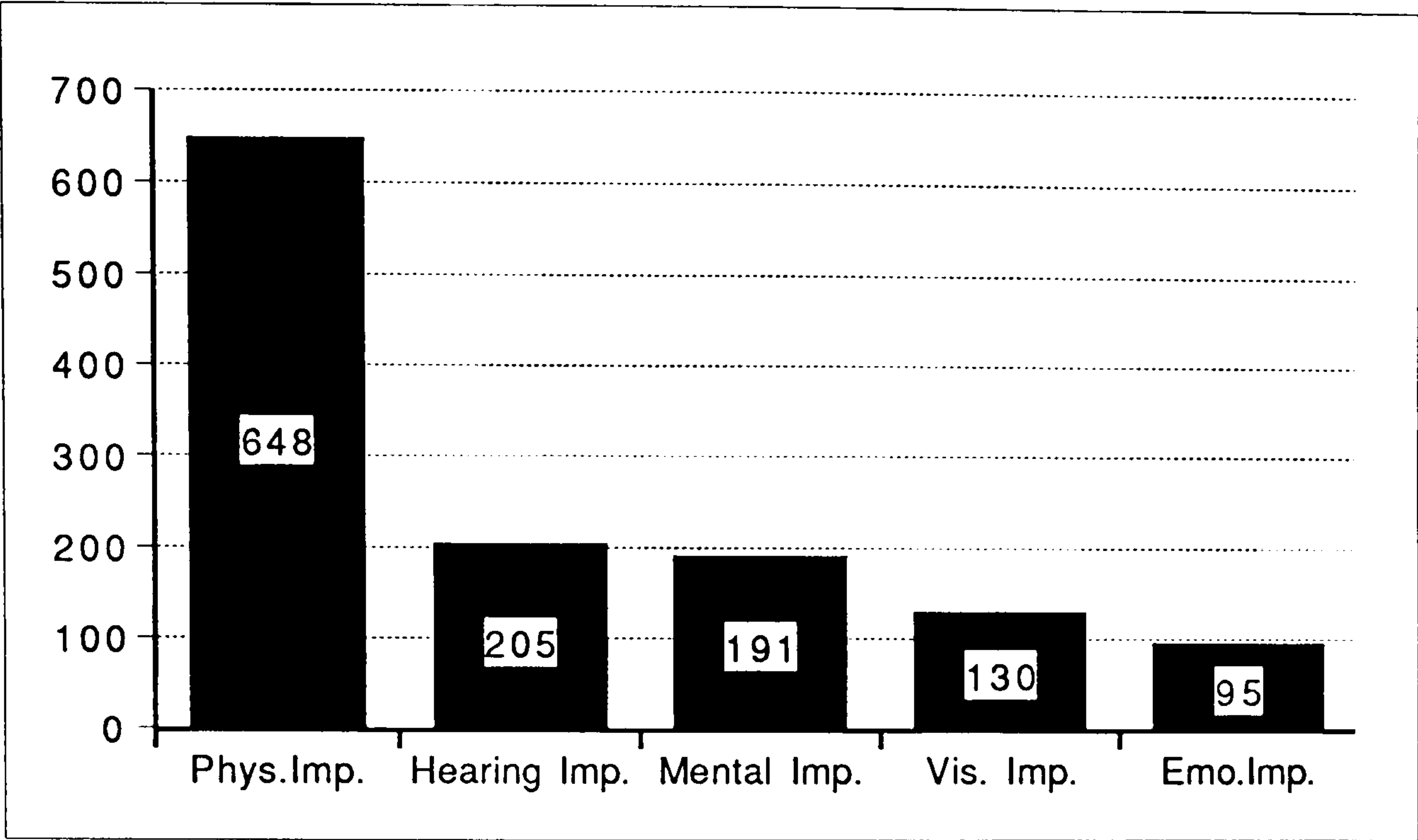
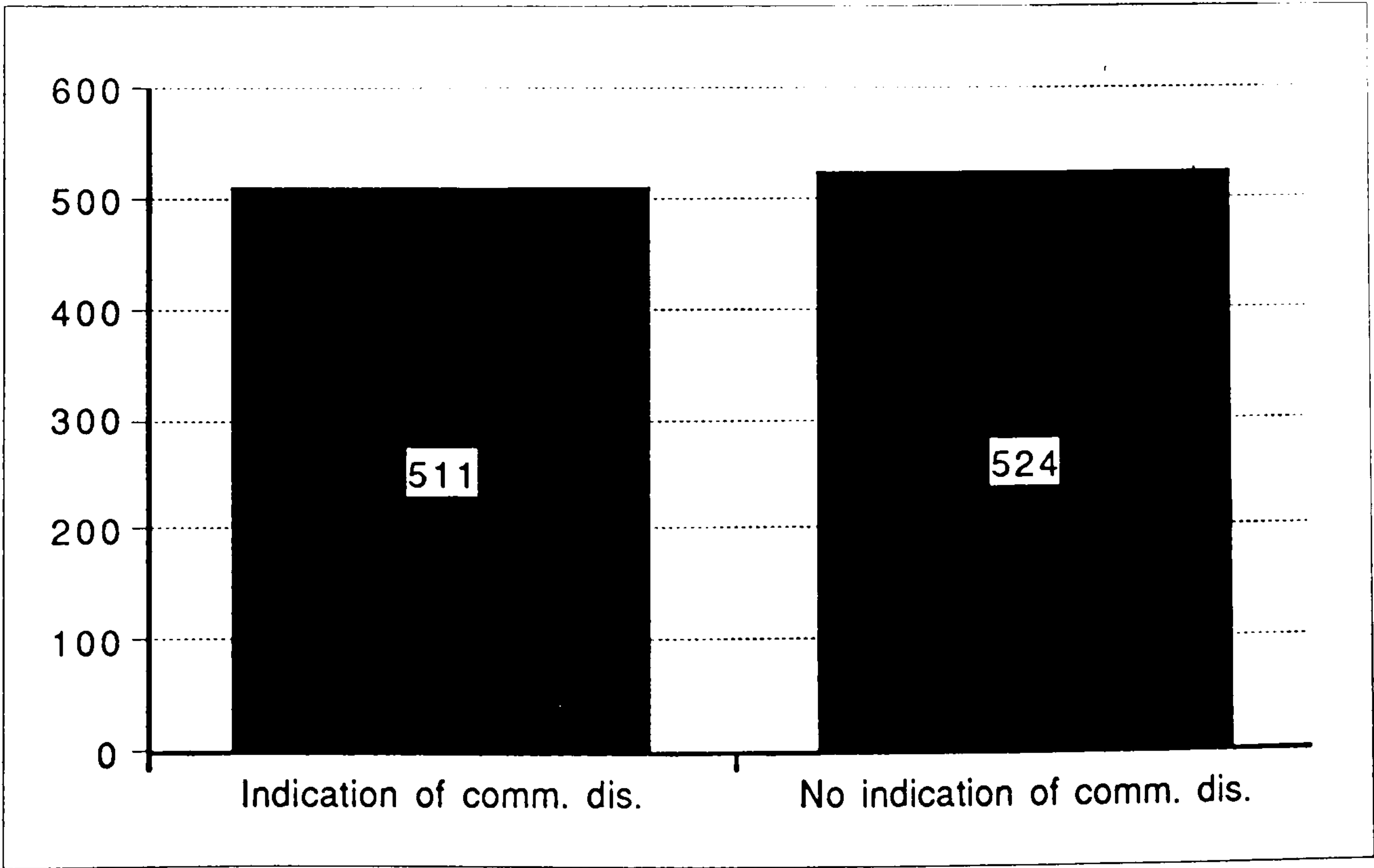


Figure10. Numbers of children presenting with indications of a communication disability, either observed or reported, for the whole group (1041).



In the process of monitoring, CDAs were randomly selected and visited. The methods used for selection are described in Chapter 4 . Table 37 indicates whether the CDAs appeared to have understood the instructions, particularly the form and the age cut off point, and also gives details of the cases randomly selected for further monitoring.

Table 37. List of CDAs monitored during data collection.

Name of CDA / Area	Problem w. form	Age OK	Name/child	Village	CD/No: cause
Mpiiya Stephen, Iganga	Yes	No	Suzani	Magada	CD Intell.Imp.
David Kateteyi, Iganga	no	yes	Isima	Ibulunku	CD Intell. Imp.
Kiirya Geoffrey, Iganga	no	yes	Ngobi	Iganga	CD H. Imp.
Namukima Gorelli Iganga	no	yes	Joy	Bulamagi	No CD Phys.Imp.
Joseph Opio, Iganga	no	yes	Silvia	Bukaye	CD H.Imp.
Khaukha Johny, Mbale	no	yes	Bisanzu	Lupido	CD Phys.Imp
John Nakedi, Mbale	no	yes	Gadi	Kwawanbungo	NoCD Phys.Imp
Wamoto, Mbale	no	yes	Morini	Shiluku	CD Intell.Imp.
Namawa Paul, Mbale	no	yes	Khaukha	Ngerebi	NoCD Phys.Imp.
Mugoto, Tororo	no	yes	Florence	Masaba	CD H.Imp.
Joseph Oguti, Tororo	no	yes	Malisa	Kwapa	NoCD Phys.Imp.
Mr. Dakkar, Tororo	no	yes	Lydis	Lujehe	CD Ph.&Vis.Imp.
John Onyango, Tororo	yes	no	Jesca	Katindi	CD Ph.&Int.Imp.

CD - Communication disability; Ph.Imp - Physically Impaired; Int. Imp - Intellectually Impaired; Vis.Imp. - Visually Impaired.

In order to verify the reliability and repeatability of the questionnaire; a random sub-sample of the total sample was identified, the researcher independently completed a survey 3 form for each of these children and the results were compared with the results gathered by the CDAs. The methodology for doing this is described in Chapter 4. This reliability check is limited by the relatively low proportion of disabled children who were reassessed, (13 out of the 1041, 1.24%).The proportion being limited by practical and



logistical considerations such as, distances involved, costs and researcher time available. Chi<sup>2</sup> analysis comparing the responses of the CDAs and the researcher showed no significant differences. Further analysis using Spearman rank correlations measuring the degree of association between the two variables are displayed in Tables 38 and 39.

**Table 38. Correlation between researcher and CDAs observations of impairments.**

Impairment Group	Spearman Rank Correlation
Physical	0.717
Mental	0.699
Visual	1.0
Hearing	0.699
Emotional	1.0

Table 38 looks at the agreement between the researcher and the CDA’s perception of the disabled child’s impairment category. A high proportion of agreement is shown overall, with total agreement for the visually and emotionally impaired categories. In Table 39 a higher level of agreement between the CDAs and the researcher is shown for the ‘reported responses’, 0 .770 agreement, indicating the proportion of parents that ‘gave the same answers’ to both parties. Inspection of questions 2 and 7 “Does the child speak at all?” and “Does/he slaver/dribble?” which showed a lower proportion of agreement in the reported responses failed to reveal an explanation for the difficulties that these questions might pose. It is suggested that alternative wording might be developed to further expand and explain these questions, minimising the likelihood for confusion.

The ‘observation responses’ of the CDAs and the researcher showed a lower, but nevertheless acceptable, overall mean agreement response of 0.507.

**Table 39. Spearman-Rank-Correlation of observed and reported scores for the 10 questions between the researcher and CDAs.**

Questions	Observed	Reported
1	0.402	0.898
2	0.253	1.0
3	0.734	0.240
4	0.413	1.0
5	0.277	1.0
6	0.497	0.558
7	0.339	0.295
8	1.0	1.0
9	0.460	1.0
10	0.696	0.712
Average mean	0.507	0.770

Inspection of the two questions with a lower proportion of agreement for the observed responses, numbers 2 and 5, showed that these questions generated misunderstanding. Question 2, “When you tell the child to do something does s/he seem to understand what you are saying?” was quite often misunderstood because it was thought not to exclude making yourself understood through signing. It is suggested that a re-wording along the lines “when you tell the child to do something, without using gesture or signs, does s/he understand what you are saying?” might be advantageous. Concerning question 5 “Can s/he say any recognisable words?” many CDAs could not see the difference in meaning between this question and the previous one , “Can s/he make himself/herself understood in words?” The pragmatic difference between ‘saying’ recognisable words and making himself understood in words was perhaps too sophisticated for such a basic tool and one of the questions could be dropped.

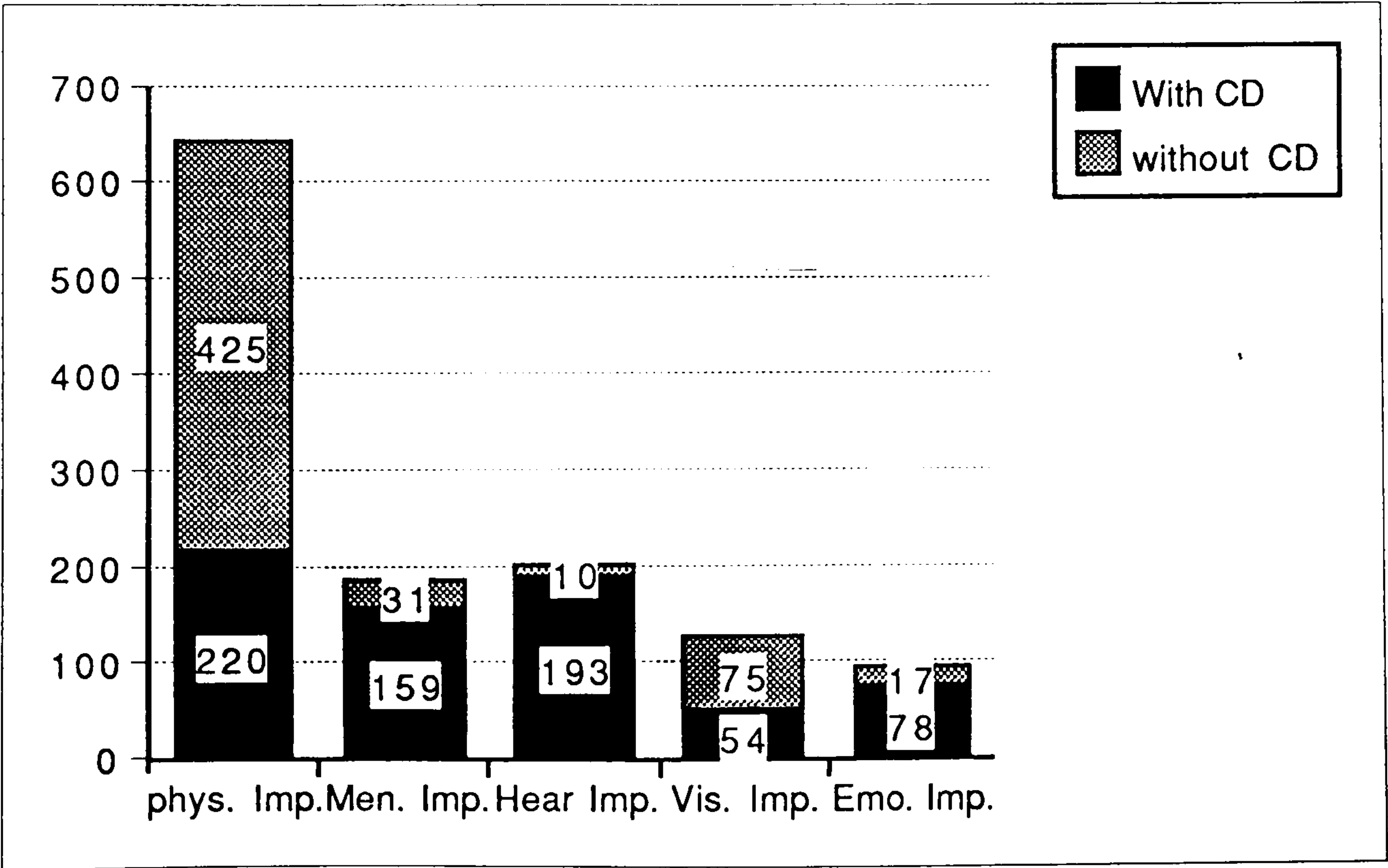
**5.7.2. ANALYSIS OF DATA COLLECTED FROM SURVEY 3.**

The information displayed in Figures 9 and 10 show clearly the different perspectives that might be gained from analysing data in these two different ways. Figure 9, illustrates the more traditional way of analysis which is often used to summarize data collected in disability surveys. (see Malawi survey Malawi (1983)). This analysis might underpin the



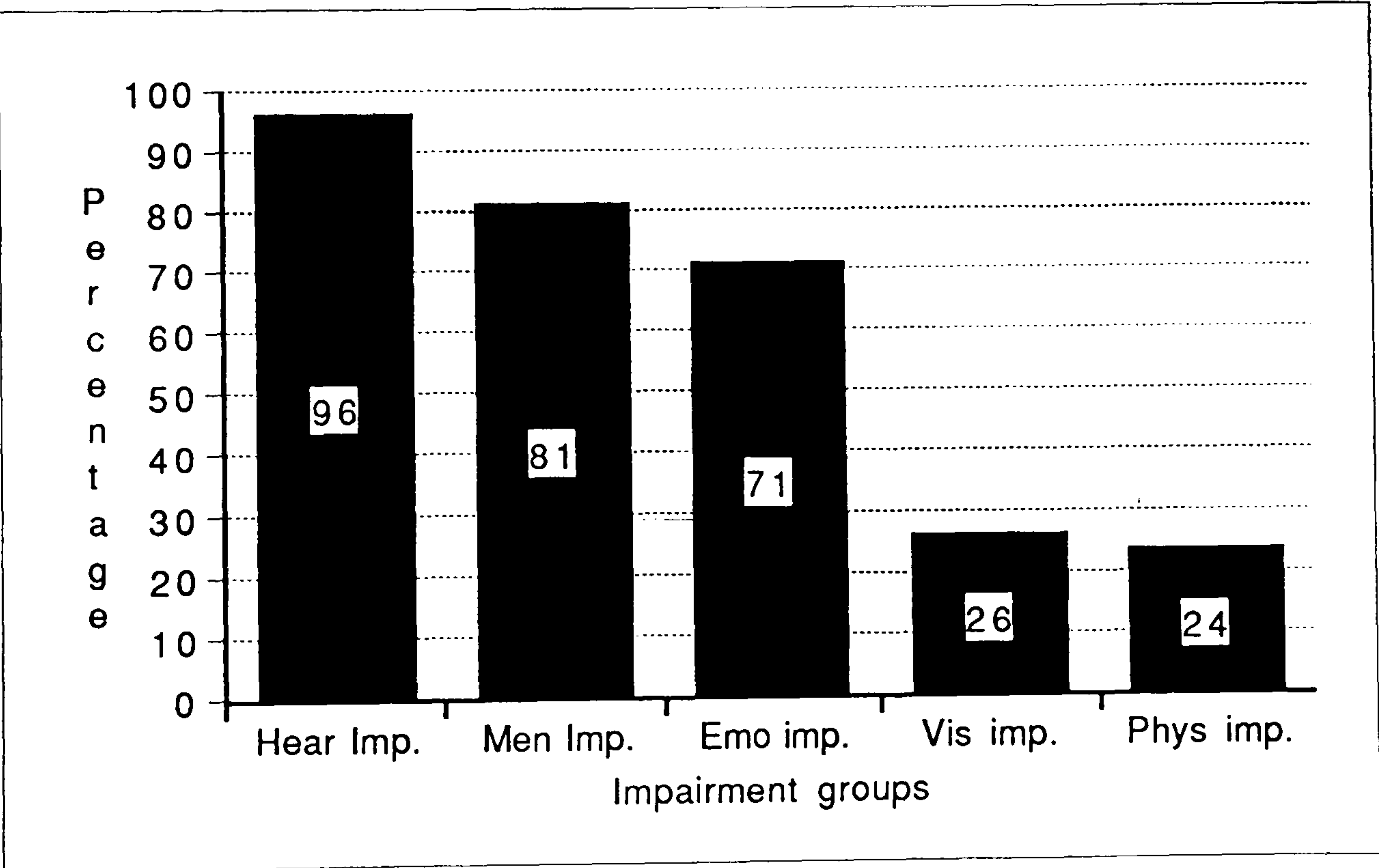
decision to develop services mainly for children with physical disabilities, as they form the largest group by a long way. The analysis shown in Figure 10, however, shows that 511 cases, i.e. 49.1% of this particular sample, displayed an indication of a communication disability. Although this is not as many as the total with physical impairments (648), it serves to illustrate that children with communication disabilities can be found within each of the traditionally accepted impairment groups as seen in Figure 11. and form the second largest group when analysed in this way. Such an analysis might produce the basis for different priorities in terms of training needs and service provision, and would give more emphasis to developing services for people with communication disabilities. It is also worth noting that of the 645 children observed to have physical impairments, 220 were observed to also have a communication disability, leaving only 425 physically impaired children who had no communication disability. This presents a smaller number than the total identified as having a communication disability.

**Figure 11. Number of children presenting with communication disability (CD) in each impairment group. (1041 children)**



Further analysis of the data looking at the percentage of children with communication disabilities within each impairment group, but disregarding those with multiple impairments is displayed in Figure 12. By disregarding the children with multiple impairments it is possible to see what percentage of each impairment group had a communication disability. 96% of hearing impaired children and 81% of mentally impaired children showing a communication disability is an expected result and as such, serves to validate the process used. What is perhaps a little surprising is that as many as 71% of the emotionally impaired also showed problems with communication, (although this is based on a very small sample, see Figure 12) and the relatively high proportion of 26% of the visually impaired against the relatively low percentage of 24% of physically impaired. These proportions have useful prediction value and implications for service development and professional training.

Figure 12. Percentage and numbers of children with communication disabilities within each impairment group, disregarding those with multiple impairments (855 children).

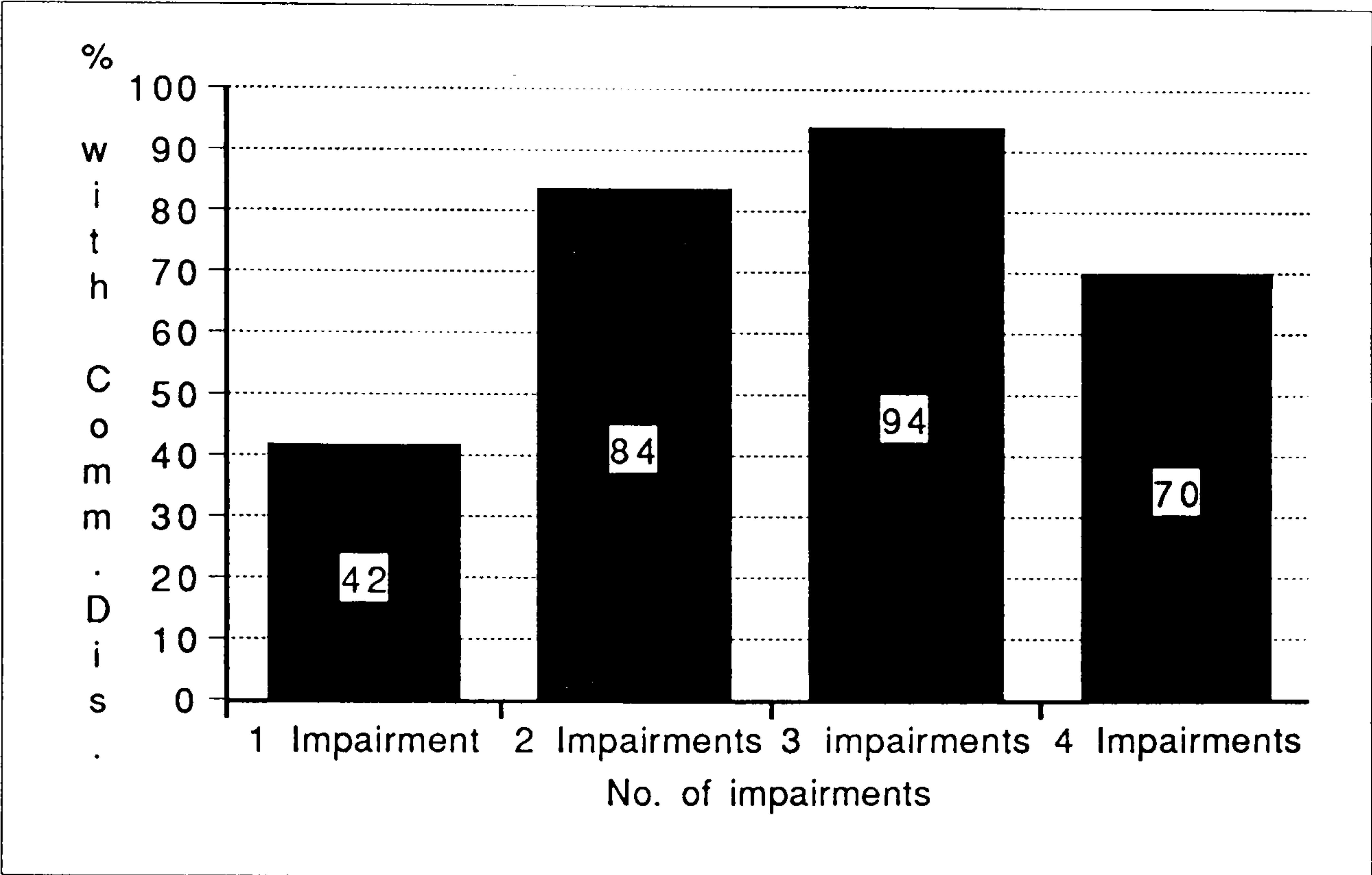


Impairment	With CD	Total children
Emo imp	15	21
Hear imp	121	126
Men imp.	73	90
Phys imp.	130	536
Vis imp.	21	82



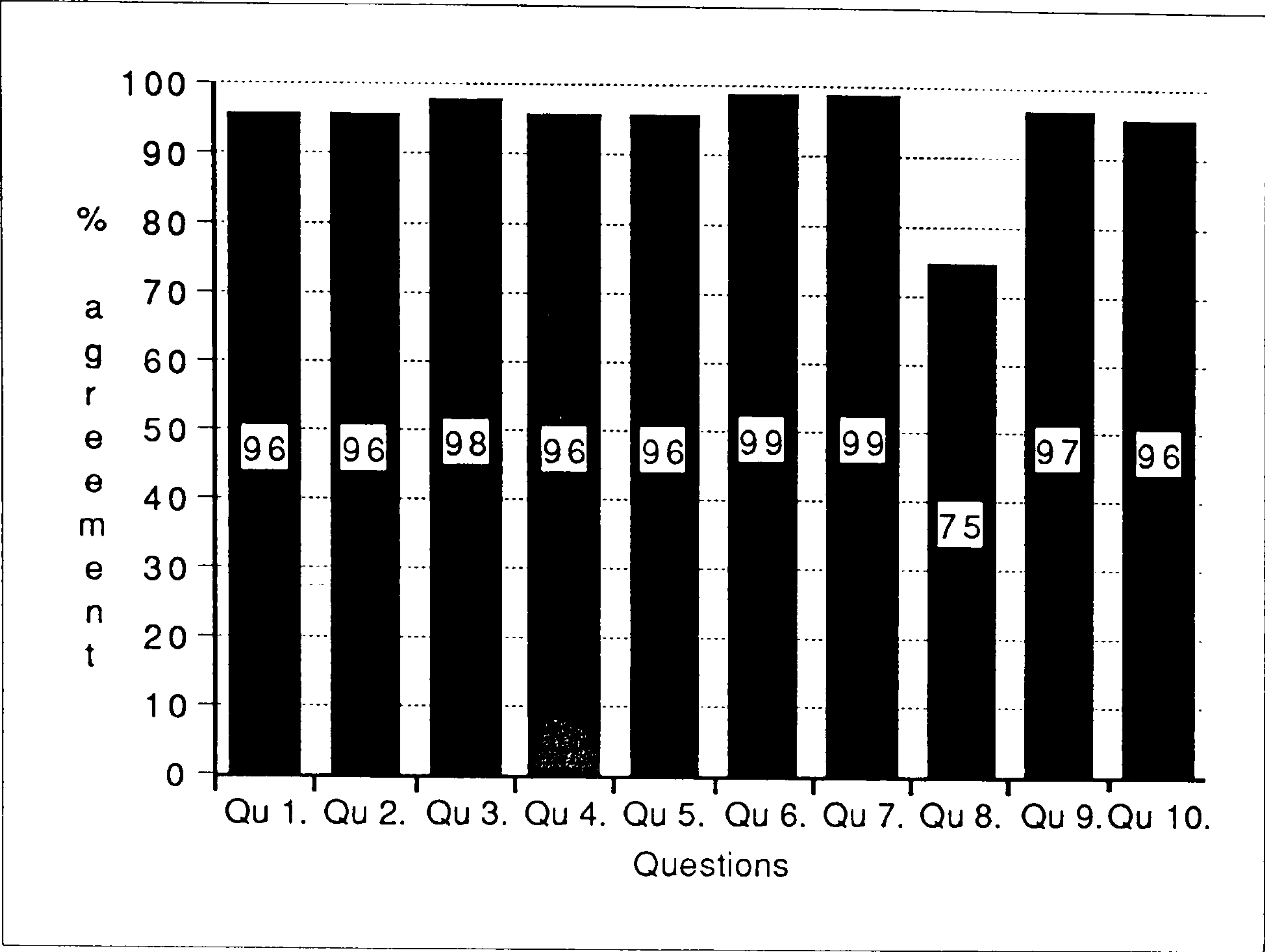
The percentage of children with only one impairment in this data sample is 83.1%. However analysis of the 511 children identified as having a communication disability displayed in Figure 10, shows that children who had more than one impairment in this data sample, had a greater chance of having a communication disability. The increase is not sustained for 4-5 impairments, but this is probably because the sample became too small.

**Figure 13. Number of impairments reported in the 510 children identified as having a communication disability.**



Speculation as to the validity of reported results as opposed to those observed by the professional worker motivated an analysis of the observed and reported scores and these can be seen in Figure 14 and Table 40. It can be seen that  $p$  is  $< 0.0001$  for all questions, indicating that the probability that they are the same is not due to chance. A hypothesis that there is no association would be rejected and a definite association is demonstrated between the two parameters.

Figure 14. Association between the observed and reported results of 10 questions.



**Note:** Question 8 has 1000 missing values due to the fact that it was only asked of clients under 2 years of age.

Table 40. Calculation of confidence intervals for survey 3.

Qu. No.	n	p	q	95% confidence interval	
				lower limit	upper limit
1	988	0.9656	0.0344	0.9548	0.9763
2	988	0.9504	0.0491	0.9365	0.9643
3	990	0.9778	0.0222	0.969	0.9865
4	991	0.9556	0.0444	0.9432	0.9679
5	986	0.9594	0.0406	0.947	0.9657
6	984	0.9858	0.0142	0.9796	0.9919
7	987	0.9838	0.0162	0.975	0.9925
8	41	0.9024	0.0976	0.8087	0.9961
9	920	0.975	0.025	0.965	0.985
10	921	0.9685	0.0315	0.9578	0.9789

T-test factor always 1.96 except in question 8 when it is 2.021.



**5.8.0. 'TRIANGULATION' ANALYSIS OF RESULTS IN RELATION TO THE ORIGINAL QUESTIONS POSED DIVIDED INTO THREE AREAS AND RELATED TO THE THREE AIMS OF THE STUDY. (see chapter 4. section 4., tables 22, 23, 24, 25 on pages 176-179 for details.)**

The observations in this section will be made in relation to the three areas identified as associated with services for people with communication disorders, namely, disability, needs/wants, and attitudes. These observations will be discussed in terms of the results gathered from the data collection related to the original questions posed. The areas of agreement and disagreement reached by the different data collection methods will be highlighted in a process of triangulation to establish validity.

**5.8.1. COMMUNICATION DISORDERS AND DISABILITY. Addressed by participant observation, key-informant, interviews, group discussions, survey 1A and 1B, survey 2 and survey 3.**

**Question 1. How are people with disability (generally) viewed in Nigeria?**

**Addressed by key informants, group discussion and survey 1B.**

The perceptions of disabled people showed many similarities to the perceptions reported in other countries, the differences seemed to relate more to degree and the stage of general social and economic development.

**Observed similarities:**

**Negative attitudes** were reported by all the Key informants, Dr. Mba observed that they are rejected by their families and Funke Sabage observed that the Yoruba word for disabled “*anebu*”, means *disgraceful, a bad mark for your family*” Prof. O. “*all disabled are stigmatized people*” In the Group discussion more negative feelings were displayed “*There are people (blind) on the road like that we do not live with them*” “*No we cannot greet them*” “*Just look and pass*”



**Shame and feelings of guilt on behalf of the parents and family.** Key informant, Funke Sabage described the attitude towards her deaf friend. *“They would always ask her to go and stay in (another )room when visitors come”* Key Informant, Prof. Ijaduola describes how children are often brought to him for help by the grandmothers *“as the children have been abandoned by their parents.”* In the group discussions parents whose children were not disabled thought that disabled children should not be part of society, obviously adding to the guilt and shame expressed by the parents with disabled children *“parents feel bad for having such a child in the family”*.

**A willingness and ability to rank the disability levels of various scenarios** was displayed by the Nigerian student groups in Survey 1. confirming the perception that the examples given were considered to be disabled in various ways to various degrees. All the scenarios related to people with communication disorders.

**Development of special institutions to cater for disabled children including those with communication disorders.** The situation analysis and participant observation revealed the existence of institutions catering for people who were considered unable to look after themselves, or unable to benefit from regular education, and were seen as needing specialist services. Key Informants, Prince Paul and Funke Sabage, both outlined the development of institutions they were responsible for, and defended their worth in terms of meeting a need.

**Charitable and patronizing feelings towards those ‘less fortunate’.** The justifications for such feelings are described in detail by two key informants, Prof. Ijaduola and Dr. Mba. Prof. Ijaduola. says that people who follow the Muslim faith ‘need to give to the poor and needy, in order to fulfil their religious duty. This perception is re-enforced by the attitudes expressed by the group of Mothers with no disabled children, who said they would give to disabled beggars if they had the money, even though they themselves were poor.

**A belief in medical help.** The medical based key informants both describe efforts made by the parents to seek their help and advice, this is corroborated by participant observation which recognises the excessive distances that people are prepared to travel in search of a cure/advice/ help of any kind. The parents of non-disabled children in the group discussion repeatedly described taking children to the hospital in search of help



and a cure . This information is re-confirmed in survey 2 by 92% of the parents recording that they had taken their child to hospital for help.

**Development of a 'professional dependent' culture.** Evidence of this is displayed in Survey 2 where parents are seen to have taken their children to a variety of professionally based services with less emphasis on utilizing the knowledge of the traditional healer. It is also reflected by parents in the group discussion, *"I would carry (him) to the hospital to get treatment... they would cure"* and by comments of key informant Funke Sabage, *"there was a women that came to me one day and pushed me into starting this programme"*.

**Low priority given to services for people with disabilities.** Reported by the key informant, Funke Sabage, who describes the difficulties of sustaining a government initiated service without dedicated workers, and the long term commitment needed to stop services from 'dying down'. Prince Paul identifies the need for the government to raise more money through taxes ( a disability tax of 1%) to fund services for disabled people. The parents in the Group discussions identify the need for more institutions where people can go for help.

**Initial development of services made by the charitable sector.** Key informants, Prince Paul and Funke Sabage, both describe the role of charities in the development of the institutions with which they are associated. This connection is also observed by participant observation in the development of schools for deaf children under missionary influence and in the details collected by the situation analysis on the numerous facilities in Oyo State that have charitable origins.

**Evidence of desire and acceptance by parents to take responsibility.**

Reported by parents of disabled children in the Group discussion.<sup>26</sup> *We should not ignore them so that they will know they are part of society" "The community / family should be enlightened that special people should be given support, special preference and all encouragement they need. They should not be treated as outcast"* In survey 2 parents show their desire to help and to be responsible by seeking help from Hospitals, Health Centres and Traditional Healers.

**Influence of the disability movement** Two of the key informants were disabled themselves, Dr. Mba and Prince Paul. The effect that this had on their lives and their own



commitment to the development of services was very evident. Dr. Mba pioneered special education in Nigeria while Prince Paul plays an active role at national (liaises with government officials) and at International (attends disability conferences as country delegate) level. At Moniya's Rehabilitation Centre Prince Paul describes the participation of many disabled people in the administration of the Centre described in the situation analysis.

### **Observed differences related to:**

**Evidence of infanticide relating to disability** was described in the literature review with reference to Miles (1989) and participant observation of children in Turkana, Kenya and also by key informants Funke Sabage *"traditionally they try to get rid of the child.. it still happens"* Prince Paul says *"they (the mission) made my parents sign an oath that they wouldn't kill me"*. The researcher's perception is that although these situations have existed and still do exist in the 'West', it is not so prevalent.

**Stronger belief in God's will results in a more fatalistic approach.** There was evidence in group discussion from both sets of parents, and from key informant Prof. Ijaduola *"There is another group of parents that feel the problem is with God" "they may go to church for a cure... the deaf will hear the lame will walk..."*

**More tolerance extended to children who are only slightly disabled.** Funke Sabage *"If the handicap is very severe you would probably want the child to die anyway, but if the handicap is slight they would rally round and help"*. Field notes of Survey 3 show integration of children into the community and an acceptance of their abilities which might not be so forthcoming in a more sophisticated society. For example FN, the deaf adolescent from Tororo district who was admired for her hard work, good household skills and cleanliness and WB from Mbale district who despite his limited intellectual capacity was accepted and enjoyed by his grandparents.

**Greater acceptance of the situation, with lower expectation levels that something can be done.** In the parent's discussion groups there was considerable reference to the situation being 'God's will' and the parents of non disabled children even went as far as expressing a reluctance to interfere. It was also observed during participant observation that parents were often very grateful for anything that you could do to help them and appreciated the smallest piece of knowledge or skill you could teach them.



## **Question 2. Can people with communication disorders be considered as part of the cohort of disabled people?**

Evidence of the existence of people with communication disorders amongst those considered disabled has been reported by participant observation of special schools in Nigeria, Kenya and Lesotho. Survey 1, with the Nigerian student professionals, ranked the main underlying causes of communication disorder according to the level of their own perception of disability and found head injury and mental handicap, the worst see table 33 page 226. The key informant observations agreed with the perception that mental handicap was the most disabling, and Prince Paul said *“those who are very hard to handle are the mentally retarded”* and discussed the difficulty of inheritance this condition caused. This was also highlighted in the group discussions by the perception that ‘crazy’ people were the most difficult to handle. In Survey 3 the perception of a high relationship with this condition and the ensuing difficulties of communicating, were quantified by community workers in Uganda, showing that 81% of the mentally impaired children in this study, were identified as having a communication disability.

The data collected by Survey 3 gave empirical confirmation that 49.1% of children brought to the community development worker by their parents as being disabled and therefore in need of assistance, were identified as having some level of communication disability. The tool used in this study was developed to detect communication **disability**, which has wider implications than just an impairment or disorder based identification tool. This issue is considered in detail in the discussion under the development of a communication disability model.

## **Question 3. Do people with communication disorders find themselves excluded from both disabled and able groups by virtue of their communication difficulties?**

Observations made during participant observation and situation analysis indicated that: Children were often accepted by facilities, for instance schools for the deaf, even when they had the ‘wrong’ impairment. In the researcher’s experience most special school



facilities accept a mixture of disabilities, regardless of the institution's declared interest. Perhaps this is due in some respect to a generally poor ability to make accurate differential diagnosis but also to a more pragmatic and benevolent attitude towards disabled people in general, together with a different perception that the needs of different impairment groups were more homogeneous than would be observed in more developed countries. The general lack of facilities often results in services developing to meet the needs presented, rather than the other way round.

Evidence during home visiting in both Kenya and Nigeria and from the Field notes of Survey 3 indicated that there were individuals with communication disorders who were excluded from daily interaction and the opportunity to participate to their maximum capability for example S. in Mbale district. Children and adults were regularly found 'locked away' in a separate room or dwelling, or tied to a tree in the compound. The reasons for such actions seemed to range from superstition and shame, to the only sensible and practical course of action given the circumstances.

These participant observations were not highlighted as areas of grave concern by information collected from the key informants who tended not to separate the people with communication disorders from people who were disabled generally.

They gave examples of both advantages and disadvantages, one of the key informants, Dr. Mba, had communication difficulties himself, but he seemed to have turned this to his advantage. He had used his own circumstances, that of acquired hearing loss, to promote and develop services and the training of professionals to assist this group of people.

Another key informant, Funke Sabage, had made friends with a deaf girl whose circumstances had inspired her to choose a career helping such people. She described the generally negative attitude of other people towards this girl, particularly the lack of knowledge and understanding demonstrated by the services offered to her. This is substantiated by the parents in the Group discussion where the Mothers indicate that their disabled children are *"in one way a blessing."*



**Question 4. How can people with communication disorders speak for themselves? Could the deaf be used as spokespeople for this group? Could parents speak for their children? (This question is addressed in the key informant interviews and survey 2.)**

The opportunity and inspiration to develop methodology to address the possibility of examining deaf people as spokespeople for others with communication disorders did not materialize but the methodology developed in Survey 2 with parents of children who had communication disorders allowed parents to speak for their children's needs. It is not known how accurately parents can express the needs of their children however useful information was gathered from this survey and observations were made more clearly and in more detail than in any other data collection method, substantiating the value of using other groups to identify needs. Parents made observations concerning the importance of long term interventions such as school, the importance of giving time, attention and loving care to the children and the difficulties of doing this without overindulging the children.

Key informant Dr. Mba through his colleague and translator Dr. Alade, describes an approach involving utilizing the strengths of certain disability groups to assist the weakness of another, for instance a mentally handicapped boy pushing the wheelchair of a physically handicapped boy. Whether this idea could be extended to deaf people being used to 'speak for' others who were not able to speak for themselves is not discussed.

Group discussions from the parents of non disabled children demonstrated an awareness of the deaf person's ability to communicate with those who were not deaf because "*you can move*" and "*we talk with our hands*", this might indicate the possibility for communication to be set up through this group of people, but what remains unclear is, would deaf people, given the more positive attitude of other people towards them, be in a position to 'speak' for other groups of people with communication disabilities? Do they experience the same difficulties?

**Aim 1. Consider 'people with communication disorders/disabilities' regardless of impairment, as a reality which encourages and allows for wider perception of the factors involved and explore this in relation to Service Delivery.**

All aspects of data collection indicated that people with communication disorders were considered to be part of the cohort of disabled people. By participant observation, key informants, in group discussions and in Survey 1, 2, and 3.

Detailed examples have already been given of the following observations:

- \* Participant observation identified this initially and played a key role in developing the idea as one which might have important implications on service delivery.
- \* Key informants highlighted the impairment relationship.
- \* Group discussants showed no evidence of making a distinction between people with communication disorders and other disabled people.
- \* Student professionals in survey 1 ranked both the causes associated with communication disorders and the degree of disability they observed in the various scenarios without difficulty.
- \* Survey 3 identified people with communication disabilities as 49.1% of the people seeking help from Community Rehabilitation workers.
- \* There was evidence that attitudes were different towards the different impairment groups.

### **Implications for service structure and training:**

The implications of this perception on service delivery are multi-faceted and allow the concepts of disability as opposed to impairment to be included for consideration in service delivery structures.

The initial phase of this research, in the literature review, situation analysis and Stages 1 and 2 of the data collection, key informants, group discussions, survey 1 and survey 2, identified a need for services for people with communication disorders to be:

1. empowering
2. utilizing parents and community



The temporal structure of this research observed that these issues were already receiving consideration by services by and for disabled people generally. If people with communication disorders could be considered part of the cohort of disabled people they would be able to access these approaches and this ideology. This disability perspective promotes a different emphasis in training, and promotes one which encompasses more community involvement and social interaction as a basis for intervention strategies and takes the emphasis away from the need for the person with the communication disorder to change, moving towards the importance and advantage of considering them as people within a society and environment which may require the intervention with these other factors as much if not more than with the person themselves. The interactive nature of communication would seem to produce circumstances where this is more imperative than in the case of physical disability. This is explained and discussed in more detail in the discussion section in Part 6.

Comparison of the analysis displayed in Figure 9 and Figure 10 of the Ugandan Survey 3. with community workers, shows clearly how the different perspective might influence the allocation of resources. The one in Figure 9 would support more resource development of expertise related to physical impairment, in terms of physiotherapists and their training, orthopaedic clinics and interventions, whereas Figure 10 would result in greater emphasis being given to provision of speech therapists and training of community workers in basic interventions relating to communication skills, alternative modes of communication, and support of the parents, family and community in order to facilitate this. This has considerable training implications.

### **Implications for intervention strategies.**

An area of concern relating to this new concept might be that intervention would be inappropriate if it was not related to impairment categories. It will be argued in the discussion that this is not the case, that impairment related intervention is often not appropriate at community level and that community intervention can introduce potentially useful information, knowledge and skills that can empower the family and alter the life experience and subsequent interaction of a person with a communication disability. It is suggested that simple and basic interventions based at a community level would have greater efficacy than those restricted to tertiary care in urban centres.



### 5.8.2. COMMUNICATION DISORDERS AND WANTS AND NEEDS. Addressed by Group discussion, Key Informants and Survey 2.

#### Question 5. What are the wants and needs of people with communication disorders in Nigeria and other less developed countries?

The data collection identified several areas of need and want. For the purpose of this study no distinction is made between the two, i.e. something you want may not be something you need. The information collected fell under the following headings:

##### Finances

Financial difficulties arising from having a child who had a communication disability was raised by the parents of such children *“there is a financial problem”* *“it stretches our finances”*. Survey 2 gives further details of some of the financial implications. The only clear indication from the data collected in this small survey of urban elite parents, is that the largest amount of money was spent on special education, 88% paid more for schooling than other forms of help, with fairly small sums on medical care and modest distances being travelled to avail themselves of such services.

Key informant, Prince Paul identified the need for finances and suggested a government solution of a 1% *“disability tax”* which he felt should be a business obligation.

##### Education

Several sources of data mentioned the importance of education for children with communication disorders:

The parents in Survey 2 rated the education they had received for their children the most helpful assistance they had obtained and placed emphasis on the importance of long term support. 14 of the 26 parents, 53% , considered education as an important need, while 19 of the 26 parents, 73%, felt they had received most support and help from the school, as opposed to services from the Hospital, health centre or traditional healer.

77% felt they received virtually no help from the Health Centre and rated this as zero.



In the group discussions they said *“they should be educated and not denied anything”*.

Parents in the group discussions emphasised the importance of education *“children should be educated “* from ‘preschool’ (Dr. Mba) and exposure to play, physical activities and experience, to ‘trade training’ (Prince Paul) described in the situation analysis.

### **Attention and affection from supportive family and community.**

Key informants and parents in the group discussion recognised the importance of supporting the family. Key informant Dr. Mba said *“I think that families should be involved”* and Dr. Alade recommended a place where families could *‘find out everything.’* The parents of children with communication disabilities however, were much more specific in group discussion and identified clearly some of their own needs and the needs of their children, as they observed them. These identified needs could form a logical basis for support and intervention. The parents’ perceptions supplied information that was not identified so clearly by other sections of this data collection.

The parents raised issues such as the difficulty of:

- coping with their own guilt and sadness.
- adjusting to the problems of restricted lifestyle as a result of a disabled child.
- financial implications, the dilemma of having to work more to find the money to pay for the extra things a disabled child needed.
- appreciating the need to spend more time with the child. *“we should not ignore them, so they will know they are part of society”* but at the same time not pay them too much attention.
- finding the extra time needed to cope with meeting the child’s needs.
- gaining the knowledge needed to help your child.
- finding someone to help you gain the ability to help your child.

Group discussion with the parents of children with communication disorders identified their children as needing love and attention, *“and also given more attention at home”* time and caring like other children but a little bit more.

Key informants recognised the importance of empowerment as a need which should be met and supported by appropriate services.

Interestingly in Survey 2 only 1 out of 26 parents itemised 'family support' as a need for their child, but at the same time they had observed that affection, extra love, more attention extra time were needed by their child, as well as talking and interacting with them. Taking these together 81% of parents felt that they needed more attention and time of some kind. However identification of who helped them with their child showed only 38% of parents received help from other members of the family, and 38% felt they received no help from anyone. This can be compared with key informants Funke Sabage, who describes the difficulties that parents can have looking after their children and how hard it is to get help and support and Dr. Mba who refers to some families' interest perhaps being related to literacy and the importance of encouraging their support.

In survey 2 when asked if the community helped to look after their child 58% felt that the community did not help at all and in the Uganda survey 3, 78.6% of the children were brought by their Mother or Father.

### **Emotional problems.**

When asked how having a child with communication disorders affected their daily lives parents of such children highlighted the '*emotional problems*' that arose and the need to deal with these.

### **Independence.**

In survey 2 parents identified 'independence' as a goal which would make their children's lives better in 13 out of the 26 families, i.e. 50%.



**Question 6. Are those wants and needs met by the services offered in less developed countries? Participant Observation, Key Informants, Group Discussion and Survey 2.**

### **Education.**

Information gathered in Survey 2 from parents of children with communication disorders indicated that the Special School to which their children went was closest to offering services which met their children's needs as they saw them. They expressed frustration with medically based services , although 77% of them had gone to a hospital or health centre first where they were offered only short term advice and intervention which was not helpful when their children had a long term condition 73% of them felt that they had received most support from the special school.

Parents of Disabled children in the group discussion identified education and more attention and affection at home, as the major needs of their children. They recognised the positive contribution that had been made by the school *“we all feel happy now about our children, compared with what we feel initially when the problem started”*.

### **Community Based Services.**

The need for community based services was identified by the key informants and this was supported by the large numbers of parents who sought help for their disabled children from the community development workers in Uganda in Survey 3. This would indicate that the need for a community based service is an issue which is not addressed when services are specialized and urban based.

### **Education versus Community support.**

The parents of non disabled children, however would not entertain leaving their children behind in the rural area if they came to the town. They agreed with the key informants, Prof. Ijaduola and Prince Paul that opportunities were better in the town and *“you can't*

*leave your pickin back*” *“better to come with you”*. The reasons for this seemed to relate to better schooling, the opportunity to teach him yourself and be with him to make sure he is all right *“too much learning all the time”* and not being left alone, *“too much alone”*. More details concerning this are given the answer to the next question.

Participant observation highlighted the lack of co-ordination between programmes and the poor level of sharing knowledge.

**Question 7. Which kinds of service come nearest to meeting these wants and needs? Group discussion, Key informants. Survey 2.**

#### **Medical versus Educational.**

Survey 2 provided data showing that the special school for children with communication disorders in Ibadan, Nigeria, was perceived by the parents of those children, as meeting their needs better than any other service they had experienced, i.e. Health Centres, Hospitals and Traditional Healers. 73% felt they had received most help from school. It highlighted their perception of the need for long term involvement for a long term problem.

It is noted that this is an urban based service and that the parents of the children who were pupils there, were representative of an urban elite. This has implications for generalizations made from this data, i.e. that the needs children from an urban elite community may be met more effectively by a special school facility than other forms of service delivery.

#### **Community versus urban.**

On the other hand, Survey 3 in the Ugandan Community showed large numbers of families seeking help from a new and emerging community service with people attending who were not in a position to utilize services in urban centres. This perception of the importance of community involvement is supported by the key informant Funke Sabage who felt locals should be involved in the services and training *‘what services do you want to render? what is your own idea of the whole thing?’*



Parents of the disabled children felt that *“the community should be able to render help for the disabled one”*. Group discussion parents felt that children should stay with their parents whether it be in the village or in the town. If parents come to the city in order to get work, the children should go too.

### **Medical services.**

Group discussion with parents of non disabled children showed several examples of their confidence in medical services. *“I would take him to the hospital for medicine” “I would carry to the hospital to get treatment”* this was accompanied by a confidence that *“they would cure”* (him) *“he would be OK”* and their confidence in special schooling *“ Yes I would take him because there are ones for children like that.”* This confidence was not shared by those parents who had actually tried the services offered by the hospitals and health centres, and disillusionment is clearly recorded in the results of survey 2.

### **Government Role.**

There was disagreement within the data collection about the government’s role. The key informant Funke Sabage and the parents in the group discussion displayed some disagreement about the role of the government in supplying services. The former was apprehensive about the government’s capability in Nigeria to control and supply such services. Some of the problems identified were lack of commitment and continuity plus an unacceptable level of corruption *“things attached to the government don’t work very well”*. She felt the development of services would be better placed in the hands of dedicated committed professionals together with the families of the people concerned. *“need dedicated people who are prepared to give continuous service over a long period of time”*. The parents group without disabled children however, felt it was the government’s responsibility to supply special services and the parents and family’s responsibility to make sure that their family members utilized these services and the parents of the disabled children agreed with them *“The Government needs to provide all the aids needed by the disabled and build more special schools”*.



**Question 9. Could consideration be given to evaluating models of service delivery in the context of what people need as opposed to what they are getting?**

**Family support.**

The parents' group discussions and Survey 2 identified needs such as extra attention, encouragement, talking and interacting as some of the most wanted needs. It would seem possible to use these identified needs as a basis for the evaluation of services and would probably indicate that more of the needs were met by the special school than any other option available, i.e. Hospital, Health centre, Traditional Healer. This would corroborate with the parents perception identified in Survey 2 that the special schools were the most helpful. It may also indicate alternative possibilities for other service delivery models, such as the development of parents' groups or child-to-child programmes. It was interesting for the researcher to observe that after the group discussions in Nigeria a number of mothers agreed to help look after each other's children informally. Many expressed their relief and enjoyment at sharing their perspectives with other parents and the teachers observed that to repeat a similar meeting might be advantageous.

In Survey 2 the parents also identified an unmet need in the low level of support they received from the community, 38% felt they received no help from anyone. There are implications for sensitizing the community as part of an intervention programme.

In Survey 2 it is interesting to note that 92% of the parents had taken their children to the hospital for help, and 50% of these children had gone to the hospital before going to other centres, 80% saw a doctor and 41% of the cases visiting the hospital saw a therapist. There was no definition of "therapist", but this was an interestingly high proportion.

**Financial.**

The parents identified limited finances as a problem facing families with disabled children. The implication of needing more resources, together with poorer opportunity to go out to work because of the home care needed by the disabled person, created a double dilemma. Key informant, Prince Paul, recognised this dilemma and suggested a solution which involved a disability tax which he thought would also meet the philanthropic and or religious needs of people to give to the less fortunate people.



**Aim 2. Explore alternative ways of measuring need which can be used to form a basis for service delivery and complement or replace information gathered or extrapolated concerning incidence and prevalence.**

Needs, mainly of parents, were identified in Survey 2, as a result of information sharing and direct questioning. This information could be speedily collected as a piece of action based research and used to influence practice within that particular institution and inform debate at a professional level. It offered no information as to the number of children and parents who live in that area who had the same problems and needs and would therefore not be of value in, for instance, determining the number of special schools of its kind were needed in that city. It did however, generate useful information about practice and structure of services e.g. perhaps special schools could benefit from undertaking to involve and empower the parents and siblings.

Identification of need as demonstrated by Survey 2 could be used as a basis to provide:

- support to parents by responding to the needs they identify,
- possible empowerment to parents by enabling the development of parents' groups,
- development of training and information sharing with local hospital and health centres and traditional healers.

It would seem that identification of need could have implications for influencing service practice which could introduce and develop structures that were more sustainable and have better coverage levels but could not identify the size or demography of the problem.

### **Need versus Incidence and Prevalence.**

Using identification of need as the basis for structure and content of service delivery would seem to add different dimensions for consideration, as incidence and prevalence only gives information about numbers and, apart from demographic information, does not help to provide a basis for the type or characteristics of the service provided.

### 5.8.3. COMMUNICATION DISORDERS AND ATTITUDES Addressed by Participant observation, Group discussion, Key informants, Survey 1 and Survey 2.

#### 10. Are Communication disordered people viewed differently in developing countries?

This question is similar to question 1 and some of the issues it raised have already been dealt with. However it has been asked again in this section to relate specifically to information concerning attitudes.

##### Cause.

Group discussion with the parents of disabled children showed that most of them felt that their children's difficulty communicating was the effect of disease *"unable to talk because of some kind of disease"* but at the same time they might *"inherit it from their parents"* there was still some evidence that some of them believed it to *"to be the work of Satan"*.

Observations made by key informants indicated a different perception of disabled people according to their impairment group, with "mental retardation" perceived as the worst kind of disability by key informants. Funke Sabage, Prince Paul and Prof. Ijaduola all referred to the person with mental retardation who had difficulty communicating as a result of his retardation being considered very negatively. However, if the communication problem arose from deafness, he was likely to be treated or regarded differently.

Group discussion with the parents of non disabled children showed no hesitation in observing that one could 'communicate' with deaf people *"We would talk with our hands"*.

##### Parents feel bad /guilty.

Many negative attitudes were identified by key informants, for example the shame of the Yoruba people concerning deaf people *"many people did not understand the problem of*



*deafness” or the blame “the whole family (is to blame).... sometimes the Mother takes the larger share of the blame”. Group discussion with parents of non disabled children supported the idea that the parents or children had done something bad. “Parents feel bad for having such a child in the family “ and were in some way to blame for their problems.*

### **God’s role.**

A great deal of guilt seemed to have a religious origin. They felt that it was God’s will and should be left to God *“we just leave it to God” “I would pray and pray and pray”* they should not interfere, although they didn’t seem to mind if Europeans came along and *‘interfered.’* This was not all negative however, *“God has helped us.” “we used to feel sad at times but they constitute a sort of happiness to us. But with the grace of God we should be able to overcome our problems” “ One day the child will talk, we have a belief in God that the child will talk” “A way of bringing us nearer to God” .*

### **Transition.**

Key informant Funke Sabage raised the issue of the effect of transition from traditional values and culture, to modern day living *“ Nigeria has changed these days, most people want to live in urban areas and because of that, a lot of these structures we are talking about have been destroyed, the kind of support that people used to have in their families, well, we don’t have that kind of support any more”* and lifestyles as an issue relating to changing attitudes.

## **11. Do the different causes of communication disorder alter the attitude of people towards the person concerned?**

Survey 1 illustrated the ability of Nigerian students to rank impairment groupings in relation to their own perception of the degree of severity associated with these groups. Key informants and group discussions agreed that certain disability groups were less acceptable in society than others and Prof. Ijaduola and Prince Paul observed the problems of

inheritance which arose when a child was mentally retarded. Mothers of non-disabled children in the group discussion also distinguished between the different impairment groups and made reference three times to responses that were related to the ability to communicate. They would not greet people who could not learn or displayed strange behaviour “*because they cannot answer you*”. They would try to communicate with deaf people as they could do this by ‘*moving*’ to say something. According to traditional stories people with a cleft palate had eaten very hot food “*so the heat of that food had entered the brain and from that the problem arose and he cannot talk*”. These parents felt that ‘*Crazy*’ people are the most difficult to handle.

**Aim 3. Consider attitudes and knowledge, about and towards people with communication disorders and the implications of these on service delivery.**

#### **Negative attitudes towards certain impairment groups.**

The negative attitude towards people with disability generally, would seem to extend to people with communication disorders, as their communication disorder might appear secondary to the underlying cause or disability about which the culture and community had views and attitudes.

The knowledge of the student professionals in Nigeria in survey 1B would appear to take on a fairly typical ‘western perspective’ and this would include their perception of disability, with no significant differences detected between the student groups.

#### **Degree of handicap.**

If a “*person is not too handicapped the community will look after it*” Funke Sabage.



## **Institutions.**

Parents of non-disabled children were in favour of building institutions where disabled people could be protected and cared for. They felt in such institutions one should *“make sure the people who look after the house keep the place clean, and food for plenty”* and that the government should be responsible *“then the children belong to the government”*.

They recognised that this would cost a lot of money but felt that *“it will stop them roaming about the country”*.

## **Abuse .**

Abuse of deaf children is described by Mr. Okurut, the District Executive Secretary in Tororo district in the Field notes of Survey 3 when he points out that it is common practice for deaf children to be used by smugglers on the borders of Uganda as when they are asked awkward questions at the boarder they could not reply and often got through unchallenged.

Examples illustrated in the Field notes of Survey 3 provided evidence of a ‘witch doctor’ who it would seem provided shelter for disabled people, a hydrocephalic boy, a dwarf and a physically handicapped man were seen to be part of his compound; others were reported but not seen. These people were not apparently part of his family. The reaction to this arrangement by the Community development Assistants was that he was an evil man using these people to frighten others as part of his traditional practice.

The field notes of Survey 3 also provided examples of negative attitudes resulting in social disgrace, for example, the young deaf woman who had married and had been returned home as unsatisfactory.

## Education.

Key informants Dr. Mba and Prof. Ijaduola and Funke Sabage felt it was very important to not only provide education for children with communication disorders but to identify and meet the need for education of parents, families and communities through the media, television, radio newspapers etc. Dr. Alade in Dr. Mba's interview. *"it is not enough to educate people in schools they do not attend long enough"*.

Key informant Dr. Mba highlighted the need for people, all people, to use sign language and to promote sign language so that deaf people could be included.

In group discussions parents of both disabled and able children felt that they should be educated *"not to constitute a nuisance to society," "they can talk again,"* but cautioned that the *"pace of progress is slow"*.

## Empowerment.

Three of the key informants expressed concerns about the importance of empowerment *"I worked hard to make it a participatory project " " ten staff are disabled themselves."*

### 5.9.0. ANALYSIS OF ALL THE DATA IN RELATION TO NEED.

On the understanding that service should be based on meeting needs, this analysis undertook to identify all the needs expressed in the data collected in this study. Examination of this data revealed that the information fell into four groups under the following four headings. Impairment, Range of functioning, Social Factors and environmental/ contextual factors.

Examples of the needs identified under these headings are listed below with notes relating to examples from the data collection:



### 5.9.1. NEEDS RELATED TO IMPAIRMENT.

As we have seen in the literature review Enderby and Philip (1986) relate their information to impairment groups and this is constantly re-enforced in the literature by the use of linguistic names developed to identify and distinguish impairment groups in relation to service delivery. Likewise, Van der Gaag (1996) when describing quality services, divide people according to impairment groups and the document she edits shows a professional preoccupation with 'disorder'. This would appear to reflect a 'need' of the professional, as the basis that this information is required for ordering and justifying service structure and intervention. This area of need is listed below together with other examples from the data.

#### \* Need for professionals to identify impairment.

- e.g. Secondary data: Literature review and situation analysis, emphasis on impairment based services and diagnosis. e.g. Enderby and Philipp (1986)  
Van der Gaag (1996)  
Survey 1A Ranking Causes.
- Survey 1B Ranking scenarios.
- Survey 3 CBR workers identified different causes.

#### \* Need for technical aids.

- e.g. Survey 3 field notes: Several children needed a hearing aid.

#### \* Need for medication / operation.

- e.g. Survey 3 Medication for control of epilepsy.  
Operation for cleft palate.
- Survey 2 Parents search for medicine.

#### \* Need to promote sign language.

- e.g. Key informants: Mba. Key informant interview  
Survey 3 field notes: Several people identified as needing, or needing to share signing skills in order to communicate.

**\* Need for interdependence between impairment group.**

e.g. Key informants                      Mba felt there was a demonstrated advantage in sharing the strengths and weaknesses of the various disability groups.

**\* Need for information.**

e.g. Survey 3    - Feeding   - e.g. Silvie .  
Survey 3    - Behaviour control.  
Group dis.   - Need information about disability and disease.  
Survey 2    - disability is long term, cannot expect immediate cure.

**\* Need for treatment of impairment.**

e.g. Group discussion - take to hospital .  
Survey 2                      - search for someone to help with impairment.



### 5.9.2.NEEDS RELATED TO FUNCTIONAL LEVEL.

That the **Range of functioning** varies according to the degree of impairment is universally accepted but the effect of the social and environmental on the range of functioning is poorly documented in the field of communication disability. The data collected in this study showed no difficulty in observing a range of functioning which is clearly demonstrated in the Nigerian survey of students knowledge and attitudes towards the people described in the 20 scenarios of survey 1B. Other examples are listed below.

**\* Parents' need for children to improve and become normal.**

e.g. Key informants - Mothers sought service for their children.

Group discussion -Mothers wanted service and help for their children so that they could improve and become independent.

**\* Need to be able to learn to read.**

e.g. Survey 2 -Parents identify this as goal of education.

**\* Need to become independent.**

e.g. Survey 2 - Parents want children to become independent.

Survey 3 Field Notes -Robert, need a role for him to play in the family.

**\* Professionals need to establish functional levels to determine and guide intervention and inform advice.**

Participant observation.

**\* Parents need to understand that there are maximum functional levels.**

e.g. Survey 2 -Examples of parents thinking that their child.

Group discussion -Would eventually be 'normal'.

**5.9.3. NEEDS RELATED TO SOCIAL ASPECTS.**

The **social interaction or participation** of the person concerned would seem to vary according to attitudes, beliefs, the degree of self help and respect. Explored in the group discussions and key informant interviews examples are described in detail such as the inheritance issue, where people who cannot communicate are considered incapable of inheriting property or position, and in survey 2 where the importance of love and attention are emphasised by parents together with the issues of isolation and rejection raised in the group discussions. Evidence from the key informants, group interviews and survey 2 would indicate that social factors contribute considerably to the communication disability and many examples can be found in the data collected. Some are listed below.

**\* Need to examine social traditions and their impact on disabled people.**

- |                              |   |
|------------------------------|---|
| e.g. Participant observation | - looking at adults is not socially acceptable which makes lip-reading an inappropriate strategy. |
|                              | - telling professionals what they think they want to hear confuses case history taking.           |
| Survey 3 Field notes         | - controlling ‘abuse’ smuggling.  |
| Survey 3 Field notes         | - banishing child to another room   |
| Key informants               | - banishing child to another room   |
| Group discussion             | - disability is ‘other people’s’ problem  |
|                              | - parents feeling guilty and responsible.   |
| Key informants               | - need for someone to be blamed.  |
|                              | - need to look for something ‘big and grand’  |
|                              | - need to give to the poor and unfortunate.   |

**\* Need for inclusion and education of parents and families.**

- |                     |   |
|---------------------|---|
| e.g. Key informants | - include parents and families in planning services |
|                     | - education through newspapers, TV etc.             |



**\* Parents need to feel that they have received the best possible care.**

- e.g. Survey 2. -search for the best 'treatment'  
 Key informants. -Ijaduola. parents impatient for immediate  
 treatment/cure

**\* Need for understanding that disabled people are 'people' first.**

- e.g. Survey 3. Field notes - deaf girl returned from marriage.  
 Key informants and PO. - evidence of infanticide.

**\*Need for family and community support**

- e.g. Key informants. - Funke "if the person is not too handicapped the  
 family would rally round"  
 - Mba "families should be involved"  
 Group dis. - should be looked after by family.  
 Survey 2. - who else helps?... not very many people.

**\* Need for disabled people to be empowered.**

- e.g. Key informants - 2 informants were disabled and had used this as a  
 basis for their work  
 Survey 3. Field notes - disabled director of Centre visited responsible  
 for its development.

**\* Need to believe in God's power or a spiritual or supernatural power**

- e.g. Key informants - Mba, curse of being disabled  
 Group dis. - God's curse  
 Survey 2. - in God's hands.

**\* Need to realize that traditions are in transition.**

- e.g. Key informant - Funke points out the problems this creates  
 Group dis. - presented mixture of values.

#### 5.9.4. NEEDS RELATED TO THE ENVIRONMENT OR CONTEXT.

The **environment** will also affect the range of function according to opportunity for interaction and physical characteristics. It is sometimes difficult to separate environmental or contextual factors from social factors, for example when does a school move from being an environmental consideration. i.e. the need for the physical presence of a school to the opportunity for the social interaction that it provides? Generally environmental factors have more obvious implications for physically disabled people in terms of access and opportunity, the role of the environment for people with communication disabilities is not so well documented. Observations made in the field notes of survey 3 would indicate that there are issues which should be addressed such as the very low light levels of the 'average' dwelling, creating additional disability for children whose hearing is impaired and who depend on a degree of lip reading for comprehension of oral speech. Examples of some of the identified needs are listed below:

**\* Need for somewhere to go for help.**

- |                     |  |
|---------------------|--|
| e.g. Survey 2       | -Need and search of parents for place that can help.                 |
| Situation analysis. | -place for people to go for help., Schools, Institutions, Hospitals. |

**\* Need for decentralized services.**

- e.g. PO & Key informants - need for rural based services.

**\* Need for 'helpful' environment.**

- |               |   |
|---------------|---|
| e.g. Survey 3 | -Cannot lip read in darkened room.  |
|               | -cannot gain experience of life to talk about if kept in darkened room and cannot move around freely. |



**\* Need for specialized services.**

- e.g. Key informant. -Mothers wanted special schools to deal specifically with their child's problem/impairment group.  
 - need to learn signing.  
 -Trade training.
- Group dis. -Wanted special schools and institutions.
- Sit. Anal. -Need for Institutions e.g. hospital services.

**\*Need for food shelter and care and love.**

- e.g. Key informant - Funke.
- Survey 2 - the parents, brother's, sisters and other children help to provide this.

**\*Need for centralized services.**

- e.g. Key informant -Mba: Centre of excellence.  
 -Paul and Ijaduola: services better in town.

**\* Need for Government support.**

- e.g. Key Informants -Money from Government.
- Group Dis. - Government should provide special schools.

**\* Need for services to be accessible.**

- e.g. Survey 2 -Parents take children where they can.
- Sit. Anal. -Under utilization of services provided in the Centres.

This analysis of needs utilizes data from all aspects of the study and serves to unite the information gathered to form the basis for a 'Communication disability model'. The model is described in Chapter 6 and uses the four elements identified, i.e. impairment functional level, social factors and environmental factors and looks at how these factors integrate together. The exact proportion of each of these elements is seen to vary from

person to person. The type, severity, degree, duration and age of onset of the impairment, can all affect the functional level of communication ability, but at the same time social factors including attitudes, expectations, knowledge, beliefs, degree of self help, empowerment levels and respect, will also alter the level of functionality. Additionally an environment which provides opportunity for communication or makes it possible through, for example, the availability of specialized equipment or access to language experience in a well lit room, will also affect the functional levels.

Adoption of this 'communication disability model' as a basis for service delivery indicates that attention and expertise need to include awareness and knowledge of the social and environmental factors influencing the functional levels as well as the impairment.



## CHAPTER 6. DISCUSSION.

*We shall not cease from exploration  
And the end of our exploring  
Will be to arrive where we started  
And know the place for the first time.*

*"Little Gidding" T.S.Elliot.*

### 6.1.0. OVERVIEW.

**Initial investigation of the literature showed:**

- confusion in the terminology used to describe the target population.
- limited information about services for people who had difficulty communicating in less developed countries.
- the causes of communicating difficulties were similar to the commonly accepted causes of disability, e.g. mental impairment, hearing impairment.

**It was observed that there was a need to:**

- develop terminology which could be used without confusion between professionals, planners and participants.
- explore the possibility of links with disability studies to access information which might be applicable to people who had difficulty communicating.
- establish base line information concerning services in less developed countries for people who cannot communicate their ideas and needs.

**Based on these identified needs the research proceeded in the following ways:**

- examination of the literature concerning the confusion of the terminology.
- investigation of the literature concerning disability in less developed countries and examination of how this information relates specifically to people with difficulties in communicating.

- situation analysis of services for people who had difficulty communicating in less developed countries.
- Identification of 13 questions which formed the basis of the research and are used as a framework for reporting and co-ordinating the results.
- Methodology to address these questions was developed in the form of key informant interviews, group discussions and surveys, with parents, student professionals and community workers.

The issues that arise from both the primary and secondary data collection in this study are discussed under the following headings. These headings reflect the conclusions of the study:

- Appropriate terminology.

- Service based on meeting needs.
- Development of a 'Communication Disability Model'.
- Application of the 'Communication Disability Model' to service structure and delivery.
- Application of the 'Communication Disability Model' to individual intervention.
- Application of the 'Communication Disability Model' to training.

#### **6.2.0. APPROPRIATE TERMINOLOGY.**

The lack of appropriate terminology to describe the target population and the difficulties this causes, has been discussed in the introductory section of this research and will not be repeated here. The discussion is placed at the beginning of the study so that the reader can follow the thought process of the researcher and be aware of the issues as the research progressed.

In brief examination of the literature concerning terminology, together with observations made in the situation analysis, by key informants, and in survey 1 and survey 2, lead the researcher to conclude that the best terminology to use for the target group was 'people with communication disability.' (Note however, that references made in the literature review and situation analysis, use the terminology of the author being quoted, and appear in inverted commas.)



The decision to adopt the terminology ‘people with communication disabilities’ was made after the first two stages of data collection in Nigeria and forms the basis for Survey 3 carried out in Uganda with Community Development Assistants. This holistic terminology allowed inclusion of all the various impairment groups described in the literature, and at the same time moved the focus away from an impairment/ disorder base, encouraging consideration of the socially interactive nature of the problems faced by the target population.

The modification of the Zaman and Kahn et al’s (1990) “Ten disability questions” for survey 3, concentrated on creating 10 questions which focused on communication. The researcher made assumptions about the validity of the questions’ capacity for representing the disability element effectively, which on reflection may not have been as accurate as first appeared. In the process of data analysis it became increasingly obvious that, using a definition of disability which encompasses social, cultural and environmental elements, Zaman’s 10 questions were ill equipped to identify these elements, and is focused at an impairment level. e.g. ‘Does the child appear to have difficulty hearing? Does s/he slaver or dribble?’ As a result, the researcher feels that the data collected in Uganda, while concentrating on communication, has moved only slightly from an impairment model towards consideration of disability as a social construct. Some of the questions do attempt to identify the ‘disability’ element for example, ‘Is the child’s speech clear enough to be understood by people other than his immediate family?’ The implication of this on the data collection is that the people identified by survey 3 are closer to those perceived as having communication ‘impairments’ rather than ‘disabilities’. A different picture might emerge if a further questionnaire more sensitive to the nature of ‘disability’ were created, giving more emphasis and attention to the social and cultural aspects of communication ‘disability’. The process of the collection of these data, however, led the researcher to consider more closely the exact meaning of ‘communication disability’ and contributes to the development of the communication disability model described in section 6.3.

### 6.3.0. SERVICE BASED ON MEETING NEEDS.

In 1975 Dr. Lambo, Deputy Director General of WHO was one of the first to observe the need for health services to address the total needs of the people it served, (Lambo 1975). He warned against the dangers of trying to solve the problem in technical and material terms and highlighted the risks involved if services overlooked the essentially human nature both of suffering, and people's reaction to the suffering, he states:

"The health status of an individual becomes meaningful only in terms of his human environment, i.e.. his social and cultural milieu". pp.7

Two decades of involvement in setting up and running services for people who had difficulty communicating in less developed countries has allowed the researcher to observe the effect of interventions which focused their energy predominantly on technical solutions and the recipients ability to change. The researcher observed that services in many different African countries had been 'imported' from other countries and were implemented regardless of local need, cultural beliefs and existing infrastructure. The wisdom of Dr. Lambo's observations had failed to penetrate to the service level addressing the needs of people with communication disabilities and evidence was needed to substantiate or refute the applicability of his observations to these services.

It is common practice for development agencies to recruit young enthusiastic expatriate professionals with limited experience of service implementation in their own country, let alone experience in less developed countries. Education in more developed countries is perceived as 'superior' to that of the LDC equivalent and such expatriate professionals are seen as suitable prospective development workers, regardless of their level of local knowledge or understanding. Such recruitment has facilitated the exportation of a 'first' world perspective and nurtured a disregard for local culture.

The skills observed by the researcher to be associated with such professionals, for example, in a speech and language therapist, a key provider of services for people with communication disabilities, are illustrated in Table 41 and should be looked at in conjunction with the



needs identified by Nigerian parents in Table 42. It can be seen that a great number of the therapists' skills relate to local culture, for example, knowledge of local expectations, what to recommend and where it can be found, or local linguistic and phonetics knowledge. Contributions made by professionals functioning outside their own cultural and linguistic base, are likely to be inadequate or inappropriate. The skills and activities of the speech and language therapist may go some way towards meeting some of the needs identified by Nigerian parents of children with communication disorders in Survey 2 and shown in Table 42, but there is a danger that many non-impairment based needs will be ignored, perhaps for no better reason than that the therapists do not have the motivation, knowledge and skills to start meeting those needs? The discrepancy between the emphasis of these two perspectives has considerable implications for service delivery.

**Table 41. Professional model illustrating activities and skills.**

Speech and Language Therapy - Professional activities	Some of the skills required to carry out this activity.
Evaluate Speech and Language	Knowledge of Linguistics and Phonetics, Normal Sp. and Lang.Dev. Knowledge of Communication disorders Knowledge of local expectations Interpersonal skills.
Case History and Social History	Interpersonal skills. Theoretical basis for observation Counselling Observational and listening skills.
Offer information	Knowledge of what to recommend Where it can be found.
Refer on	Knowledge of what should be offered Knowledge of what can be offered.
Teaching/Therapy	Speech Pathology knowledge and skills.
Counselling	Listening skills Providing impartial information Accepting situations Respecting different perceptions. Re-assess Desire to be accountable Skills listed under 'evaluate' Discharge Knowing Limitations.

If service is to be based on needs, the questions must be asked: Are professionals providing service on the basis of their own skills and knowledge, rather than responding to the needs of the group of people they are there to assist? And, if they decided to respond to the peoples’ needs, do they have the skills to meet these needs? Could they, or even should they, access the skills and knowledge of other groups of people, such as community workers, parents and children? Would the needs of their ‘client group’ be better served if they became advocates and partners rather than specialists and experts? If they decided to function in this different way, does their training and education provide them with the ideology, knowledge and skills necessary to carry out this alternative role? These questions will be discussed in more detail in the following sections.

**Table 42. Wants and needs of children with communication disabilities as identified by their parents in survey 2.**

1. Access to Education
2. Teachers and Therapists to teach them how to speak
3. People to listen to them
4. People to spend time with them
5. Opportunity to become productive members of society
6. To be part of the family
7. Ability to earn money and look after themselves
8. Love and care

This research was undertaken to identify areas of need in a target population, and through focus group discussions, key informant interviews and surveys with people involved in providing or receiving service, and to establish the details of these needs. The analysis described in the previous section showed that a large proportion of the issues raised, relate to four considerations, impairment, functional level, social factors and environmental factors. The connection between these components and the different types of data collection is displayed in Table 43.



#### 6.4.0. DEVELOPMENT OF A COMMUNICATION DISABILITY MODEL.

Development of a model as a basis for ordering and understanding the process of communication in relation to spoken language is explored by Crystal (1989). Crystal recognizes the scientific importance of searching for fresh models in order to provide a conceptual basis for predicting behaviour and feels that 'language pathology' is no exception. He describes the study of patterned human communication in all its modes as 'semiotics' and distinguishes it from the study of 'Zoosemiotics,' animal communication. Crystal's (1989) communication model highlights the interaction and contribution of the auditory, visual, tactile, olfactory and gustatory avenues, but does not include what he calls 'behavioural aspects' until he considers a 'linguistic disability model' In his 'models of language disability' he suggests that the components may include, social, linguistic, psychological and bio-medical factors, although he does not carry the implications of his observations through to clinical practice or professional training.

The development of a 'communication disability model' arose from the data collected in this study and provides a response to the need for terminology which could be used to refer to people who have difficulty communicating, regardless of cause and regardless of the avenue of communication. The model provides a vehicle for understanding the holistic perception required, lessening the confusion that exists and facilitating the collection of meaningful data and information which can be used to facilitate better service delivery.

As we have seen from the literature review and the data collection, the disability perspective provides a more holistic and socially oriented view, based on the identified need to clarify the meanings of impairment, disability and handicap, inclusion, enabling and empowering. These concepts have been explored and the data collected about the target population have contributed to the development of the proposed model.

To illustrate this point data collected in this study indicate that any new model of service delivery must :

1. Utilize the family and the community - Key informants, parent group discussions
2. Empower the disabled people themselves - parent group discussions, survey 2
3. Establish needs and wants - survey 2
4. Change attitudes by improving knowledge and increasing access to information - Key informants

These observations comply with the disability perspective described by Helander (1993) and are also reflected in the UN Standard Rules for Equalization of Opportunities for Persons with Disabilities (1994). Even Disabled People International (DPI) identify and support these issues, in spite of disagreement about the professionals' manner of implementation. The researcher feels that the reviewed literature together with the data collected in this study, particularly Survey 3, establishes 'people with communication disorders' as part of the cohort of disabled people, thus it would be more appropriate to refer to them as 'people with communication disabilities'. She identifies the reasons why this perception is to their advantage in terms of better access to services , meeting their needs and improving attitudes.

Examination of needs provided the basis for identifying four key areas of service concern; impairment, range of functioning, social factors and environment. The details of the data used to identify these areas has been described in Chapter 5 and a summary of the source of this data is presented in Table 43. This information forms the basis of the communication disability model, which is displayed in Figure 15.



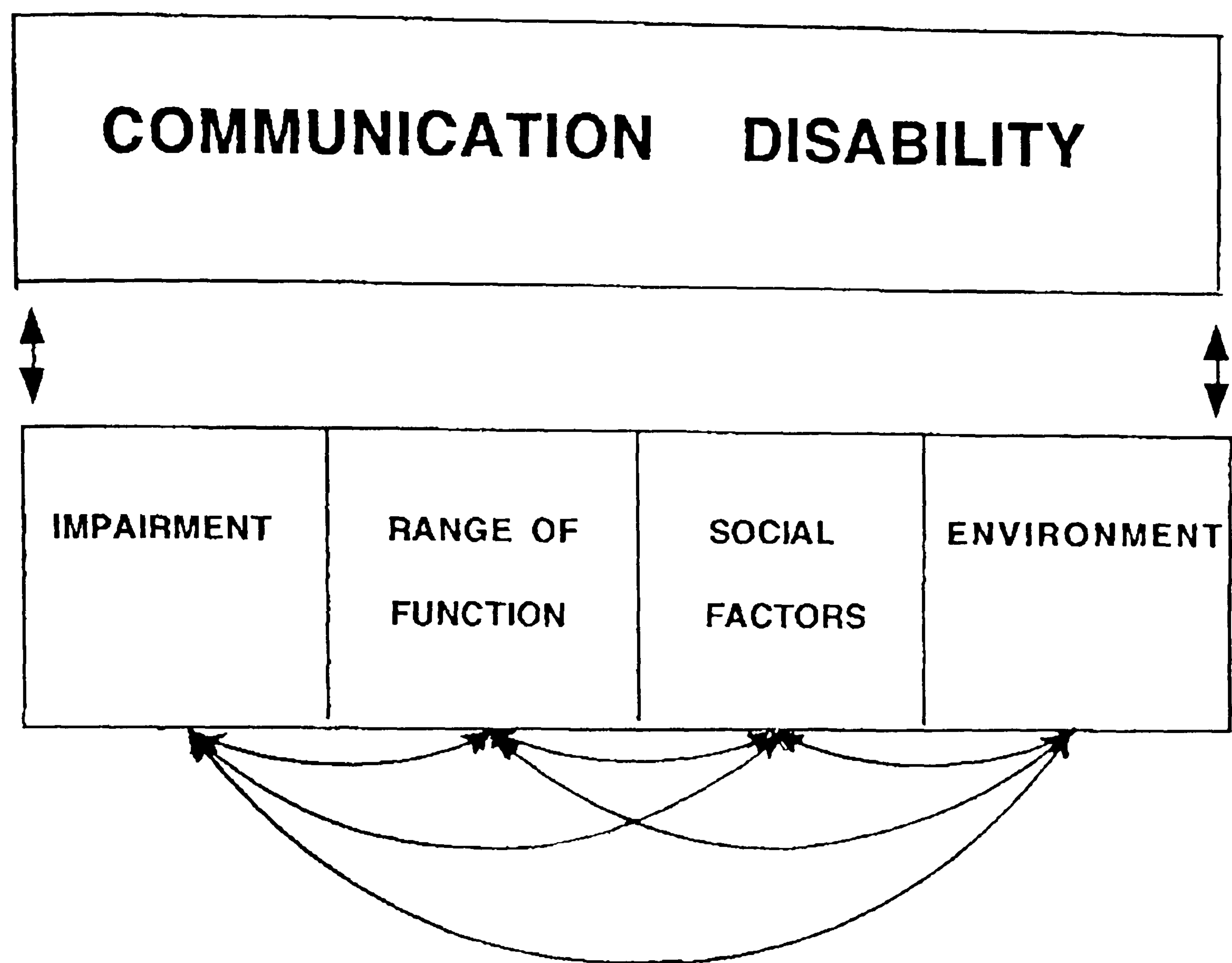
**Table 43.** Illustrates the components of the 'communication disability model' and the different aspects of this research where these components have been identified and discussed.

Areas of identified need form components of the 'Communication Disability Model'	P A R T I C I P A N T  O B S E R V A T I O N	Illustrated in different aspects of this research
Impairment		- Literature Review - Key informants - Survey 1A - Survey 3
Varying Functional levels		-Survey 1B -Key Informants -Survey 2 and 3 -Field notes
Social Factors		- Key Informants - Group Discussions - Survey 2
Environment		- Situation analysis - Survey 2 - Survey 3 (Field notes)

The communication disability model arising from this research follows the biopsychosocial model which is described by Engel (1980) and McWhinney (1989) and is based on the general systems theory described by von Bertalanffy (1968) which recognizes that all of nature is organized according to a hierarchy of systems moving from the cell, to tissue to organ to person to family to community to society. Von Bertalanffy (1968) says that each level is both a whole in itself and part of a greater whole. This view would seem to support this proposed model and emphasize the need for inclusion of the disease and impairment element of disability as an entity which should be given consideration along side systems further up the hierarchy, in order to achieve the whole picture. It is the appropriate balance or emphasis of the various parts of the 'whole' which is crucial for the development of appropriate service structures. This balance is often skewed to the cell and tissue level within the medical field.



Figure 15 Communication Disability Model.



Knowledge and understanding of the actual impairment which underpins the disability, forms a significant part of the knowledge base and structure of service offered by professionals, but this model suggests that an understanding of functional levels, the contributing social and environmental factors are also needed, as they underpin the disability also. This model provides a frame work from which this can be addressed.



### 6.4.1. COMPONENTS OF THE COMMUNICATION DISABILITY MODEL.

#### The Impairment.

Historically, rehabilitation services have developed from an expansion of the medical profession, (Oliver 1990) and have therefore been forced to justify themselves against medical model perceptions. An example of this can be seen in the work of Enderby and Philipp (1986) who relate all their information to impairment groups. Identification of the impairment forms the basis for diagnosis in the medical model and Crystal (1989) argues that a professional involved with people who have a 'linguistic disability' need to be conversant with this frame of reference as in a large proportion of 'cases', some medical condition is involved.

Consideration of 'impairment' as being just one part of the model moves away from its present dominance reflected not only in professional codes of good practice (van der Gaag 1996) but also quite dramatically by Raaijmakers, Dekker Dejonckere and van der Zee (1995) who undertook to look at the reliability of speech and language therapy assessment of impairments, disabilities and handicaps as defined by the WHO (1980). The results show a staggering 90 different observable impairment categories, as opposed to 11 for disability and 3 for handicap. The perception that the impairment may only be part of the picture provides an immediate explanation as to why 'impairment based services' may have limited impact and why in certain circumstances those services may be underutilized. It would suggest that services based on 'impairments' only, address just one part of the identified needs, and as we have seen in survey 2 with Nigerian parents, this area of need is not always the one viewed as the most crucial or important by the users.

The model does not, however, support the idea put forward by Finkelstein (1989) that disability is the creation of society's reaction alone, and recognizes that the 'impairment' is indeed part of the 'whole'. Identification of the impairment, stabilization of a medical condition, treatment of related illness are often entirely appropriate, but such interventions should be viewed as part of a larger picture.

We know that concentration on an impairment based model requires tertiary (highly skilled) knowledge based services. The model developed here suggests that impairment based intervention addresses only a small part of the issue and it might be that other aspects of the model, are more appropriately handled by other workers, or even relatives friends or communities.

We have seen in the situation analysis in Nigeria that existing service structures concentrate on impairment, for example the Speech and Hearing Clinics and Special Schools for the Deaf tended to leave the other components which contribute to the disability, unaddressed i.e. social and environmental factors. Energy and expertise has concentrated on knowledge of the impairment base from which it was felt the restriction of function originated. This knowledge is powerful and supports professional dominance. Service has developed round this dichotomy.

That the **Range of Functioning** varies according to the degree of impairment is universally accepted, but the effect of the social and environmental factors on the range of functioning is poorly documented in the field of communication disability. The data collected in this study showed no difficulty in observing the range of functioning which is clearly demonstrated in the Nigerian survey of student's knowledge and attitudes described in the 20 scenarios of survey 1B.

Awareness of the maximum and minimum functional levels, given the impairment and the social and environmental factors, underpin intervention targets and should not be underestimated, but again knowledge of both the impairment limitations AND the social and environmental factors are needed to make this judgment. If these judgments are based only on impairment information errors are likely to occur. For example parental expectation in survey 2 that their children would eventually be all right, were likely to be unrealistic.



**The social interaction or participation** of the person concerned would seem to vary according to attitudes, beliefs, the degree of self help and respect. Explored in the group discussions and key informant interviews, examples are described in detail such as the inheritance issue, where people who cannot communicate are considered incapable of inheriting property or position, and in survey 2 where the importance of love and attention are emphasised by parents, together with the issues of isolation and rejection raised in the group discussions. As we have seen in the analysis, evidence from the key informants, group interviews and survey 2 would indicate that social factors contribute considerably to the communication disability.

**The environment** or contextual factors also affect the range of function according to opportunity for interaction and physical characteristics. Environmental factors have more obvious implications for physically disabled people in terms of access and opportunity, the role of the environment in communication disability is not well documented. Observations made on the field trips during survey 3 would indicate that there are issues which should be addressed such as the very low lighting levels of the 'average' dwelling, creating additional disability for children whose hearing is impaired and who depend on a degree of lip reading for comprehension of oral speech. According to Woodhead (1996) exploration of the ingredients of the environment which contribute to or detract from children's development should be based on contextually appropriate quality standards, built on the local child-rearing standards that have developed over generations and at the same time take account of changing social and economic factors. He argues that this will render some traditional practices inappropriate, but also provide the basis for innovative development. Further research is needed in this area to establish what factors in the environment affect children with communication disabilities and what strategies would be practical and culturally acceptable.

Evidence from the group discussions and situation analysis highlighted some issues for consideration:

- physical segregation of the different impairment groups in special schools,
- the parents, brothers, sisters and other children that are the helpers,
- people cannot access the skill of signing easily,
- children themselves cannot move around and therefore be part of society and gain experience on which to base the development communication ability.

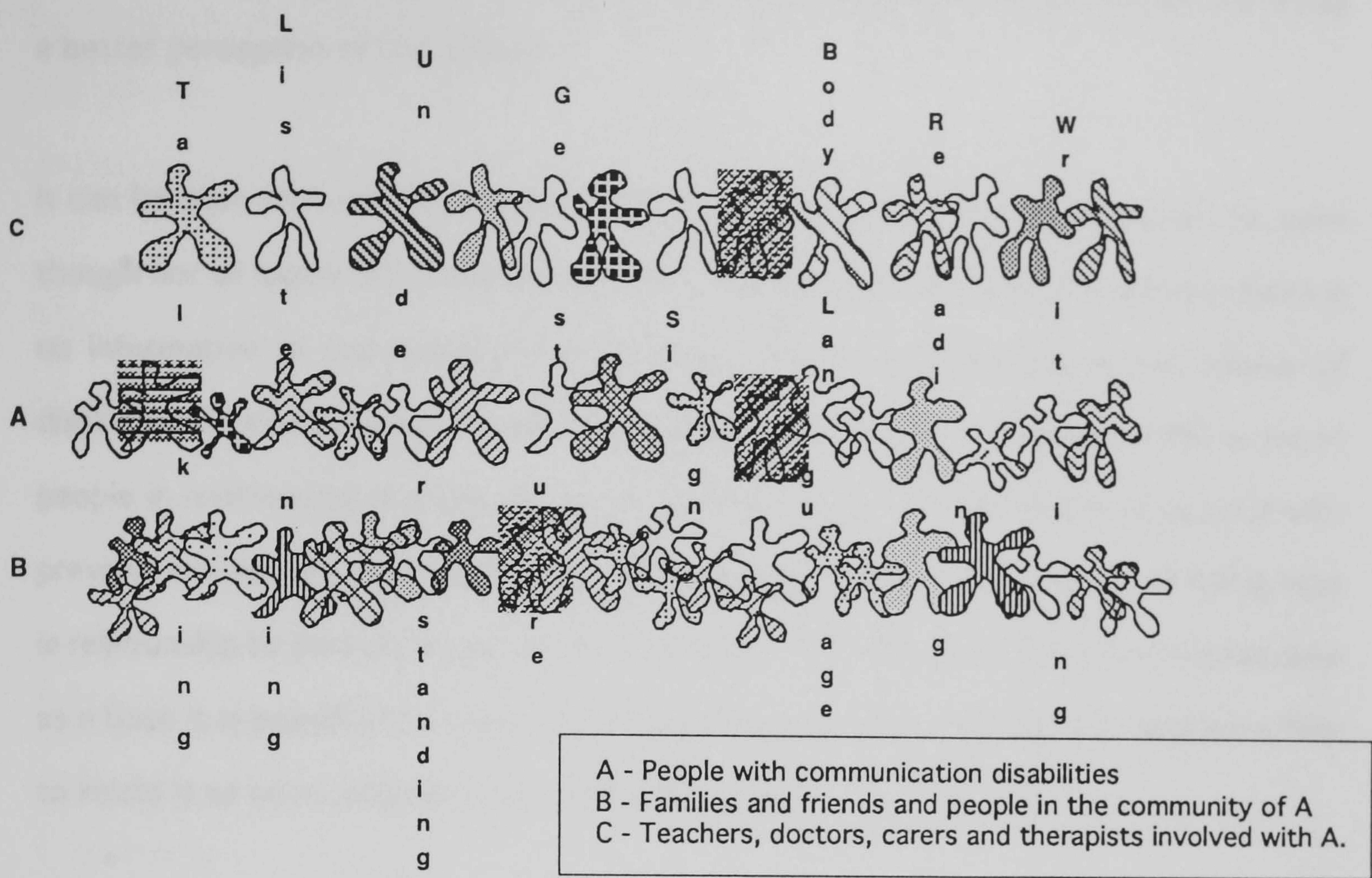
It is likely that the exact proportion of each of the areas identified within the communication disability model are likely to vary in each case, and the various components will be interactive as indicated by the arrows on the model. The type, severity, degree, duration and age of onset of the impairment, can all affect the functional level of communication ability, but at the same time social factors including attitudes, expectations, knowledge, beliefs, degree of self help, empowerment levels and respect will also alter the level of functionality. Additionally an environment which provides opportunity for communication or makes it possible through for example the availability of specialized equipment or access to language experience in a well lit room, will also affect the functional levels.

The data collection in this study has taken a number of small 'snap shots' of different parts of a larger structure. An attempt has been made to develop a visualization of this 'whole' to illustrate perspectives not covered in the previous model, but illustrated by data collected in this research. It is presented in Figure 16.

The holistic perception represented by this model allows one to view the entire target population and provides a starting point for assessment of the smaller groups within this model. It also allows reflection of how this group may relate to other groups e.g. people with communication disabilities with other disabled people, or its environment, people with communication disabilities within the educational system. These seem important relationships to explore if services are to be advanced.



Figure 16. Visualization of Communication Disability



The central line of figures, (line A) represent people with communication disabilities, they come in many varieties related to different impairment groups, at different times in their lives for different periods of time. They relate mainly to two groups of people:

- their families and people in their local community, they are represented by the line of people underneath. (line B)
- They also relate to professionals, teachers, doctors nurses, therapists, represented by the line of people above. (line C)

They relate with these people through various channels of communication, talking, listening understanding, seeing, gestures, body language, sign language, reading and writing, these channels are written across and through the three lines of people.

The data collected in this study has looked at various aspects of this model, for example, Survey 1 looked at the knowledge and attitudes of student professionals and represents information about line C in relationship to line A. Survey 2 looked at the parent's perceptions of their children's needs and represents information about line B in relationship to line A. Survey 3 looked at the proportion of line A in relationship to people with other disabilities



as seen by community workers who are represented in line C. Each of these small studies produced a snap shot of part of this model and the information has been used to build up a better perception of the whole.

It can be seen that this visualization of communication disability is a complex one, even though not all facets of its dimensions are represented in this model, for example there is no information or representation here about underlying impairment or the degree of disability. It does however provide a perspective that allows us to observe this group of people in relationship to other groups of people, without the limitations associated with previous studies who focus on one particular group. It allows consideration of this groups in relationship to their environment , or social and cultural situation. Using this visualization as a base it is possible to collect more information about specific aspects and know how to relate it to other aspects to confirm the 'whole'.

#### **6.5.0. APPLICATION OF A COMMUNICATION DISABILITY MODEL TO SERVICE STRUCTURE AND DELIVERY.**

**The questions should be asked.**

Do the 2% of people who receive services benefit from these services? Are these services wanted and needed by the other 98% or would they benefit from a different kind of service? Do the 98% access other kinds of services? If so what are they? Are they satisfactory? What could be done to alter existing western based services to give better coverage levels? In what way can one method of service delivery complement and facilitate another?

Survey 3 in Uganda used the perception of 'people with communication disability' as the basis for collecting data . The new perspective allowed information to be presented in relatively non-impairment related way and showed that people with communication disabilities formed 49% of the disabled people seeking help from Community Development Assistants (CDAs).



Application of this prevalence rate enables estimates to be made of the number of people who are likely to have a communication disability using locally collected figures relating to disability. Some examples are given in the Table 44.

**Table 44. Prevalence of children with communication disabilities in a number of LDCs.**

Country	Prevalence of disability *	Total Population **	No. of disabled people	40% children (UNESCO) ***	49% of disabled children have CD.
Uganda	5.2%	18.44m	958,880	383,552	187,940
Nigeria	5%	109m	5,450,000	2,180,000	1,068,200
Swaziland	2.5%	.76m	19,000	7,600	3,724
Ethiopia	5.5%	46.743m	2,570,865	1,028,346	503,889
Zimbabwe	3.4%	9.12m	310,080	124,032	60,775
China	4.9%	1,139.1m	558,159,000	223,263,000	109,399,160

- \* Disability prevalence rates taken from UNESCO (1990)
- \*\* Populations taken from Instituto del Tercer Mundo (1994)
- \*\*\* proportion of children in a given population taken from UNESCO (1990)

It is appreciated that figures collected in Uganda and extrapolated to the situation in other less developed countries may not be very accurate, but they do provide a basis on which to estimate the likely number of children with communication disabilities. It is important to note however that no predication is made about the proportion of these children who would benefit from service intervention, but the researcher would argue from her own experience and observations in the field work of this research that this is likely to be a high proportion.

An estimate of the numbers provide the planner of the service with an idea of the size of the need on which service structure and delivery should be based. As we have seen, the other data collected in the process of this research was used to formulate a communication disability model which indicated that service related to needs only requires the highly technical approach for a small proportion of the identified needs i.e.. at the impairment level. The combination of these two new perspectives could form the basis for a different focus on service development for people with communication disabilities particularly in less developed countries.

It can be seen that nearly 190 thousand children have a communication disability in Uganda where one expatriate speech and language therapist holds one clinic once a week in the main centrally located tertiary hospital of the country. This immediately alerts the onlooker to the service structure dilemma. It is evident that in the foreseeable future the possibility of developing the skilled and technical interventions associated with individual therapy from a specialist for this number of children is an unrealistic expectation. Decisions need to be made as to what extent other workers can be trained to help people with communication disabilities, who these workers might be, what sort of training they require, who should train them, what should they be expected to do and how this would fit in with other service structures in the country? In Uganda a Danida funded project in conjunction with the Ministry of Education is helping to train special education teachers in assessment and basic intervention with disabled children, including those with communication disabilities. The teachers trained on these courses will be deployed in Educational Assessment Resource Centres being established all over the country. The present speech and language therapist has in put into this training. In other countries it might be found to be more appropriate to train health or social workers to carry out these tasks, this would depend on the structure of service and expertise available in the country. These issues need to be considered by the local people in the light of local information, local expertise and interest available.

In order for such training programmes to develop there is an obvious need to establish what training is required and to identify a group of professionals to carry out this training.



**Questions which need to be considered as a basis for developing appropriate and sustainable service structure.**

### **Should services be urban based or rural based?**

The data collected from key informants and parents in the group discussions gave a variety of perspectives concerning urban versus rural based services. The logical conclusion from the information is that both types of services are needed, but that they should be developed in relationship to the need. The imbalance of provision that has evolved with over centralizing of services, needs to be rectified. Nor does it necessarily follow that rural based services should to be the same as urban based services, locally collected, area specific, information should provide the basis for service provision.

### **Who should train people to provide service?**

Who is the best person to train and co-ordinate services for people with communication disabilities? If it is the Speech and Language Therapist (SLT), does she need different orientation and training? If it is the community worker, do they need more knowledge and skills to maximize and facilitate communication activities? If it is either or both what structure is needed for them to work together effectively?

### **Who should carry out the service at the 'user' level?**

Which community worker is best placed to provide service? A specially trained community rehabilitation worker? Or someone already in the system? Perhaps a nurse, or is the teacher better placed to perform this role? Do they have the training and skills to do this? Do they need more technical support? Can they give the individual attention required?

### **Who should co-ordinate the services?**

The role of the Doctor requires investigation and discussion. The data collection showed that in Nigeria the majority of disabled children were first taken to the doctor but that the help they received from them was limited. Should he be in charge of co-ordination of the service to this group? This dilemma would appear to exist in more developed countries too, and is highlighted recently by Memel (1996) who observes that here in the UK the general practitioner is often the only source of health care for disabled people and the General Practitioner is the

gatekeeper to other services. He advocates the need for general practitioners to have a greater knowledge of the functional and social aspects of disability as a means of improving the quality of care. If the Doctor is to act as 'gatekeeper' does he have the training or the time to perform this role in LDCs? What training would he need to carry out this role effectively?

Perhaps the Speech and Language Therapist is the best person to coordinate such services, with a thorough understanding of the elements of communication and listening and therapeutic skills and an appreciation of the consequences of devastation that a breakdown in communication ability can create?

Perhaps the first step towards the development of a service structure is to identify who is going to be the co-ordinator of the service, and who is going to be the advocator and speak and communicate for those who cannot?

**How can the incompatibility of the views of professionals versus disabled people be resolved?**

**Views of the professional include:**

- \*Defend 'standards' while delivering services with low coverage levels. (Helander 1993).
- \*Defend and perpetrate medical perspective and as a result impairment related activity predominates. (Oliver 1990).
- \* Reluctance or lack of skills to get disabled people involved. (Finkelstein 1989).
- \* Desire to label and diagnose e.g. articles in recent journals do not pay much attention to identification of needs, efficacy of treatment, service structure and development.

**On the other hand the priorities of disabled people themselves as expressed by Disabled People International (DPI) (1989) are:**

- \* Rejection of labels used by professionals.
- \* Rejection of patronizing approach.
- \* Empowerment.
- \* Enabling.
- \* Recognition of social elements.



Suggestions from Chambers (1993) and Coleridge (1993) about developing a 'new professionalism' which does not dominate, but develops and values skills that inform, empower and enable others, have started to identify positive ways of tackling the discrepancy between the groups.

### **How can families and communities be used to help?**

Evidence from this data collection identifies the willingness and interest of the families to be involved, while it produces limited evidence of the community's desire to be responsible. The questions should be asked? How can families be helped? Can communities be educated into taking on responsibility or is this unrealistic? How could they be involved?

The high association between observed and reported responses in Survey 3 is a significant finding for service delivery issues of identification. The finding is substantiated by the original research by Zaman et al (1990), indicating that disabled people can be identified without sophisticated and specialised analysis. Data collected in recent study by Bellman et al (1996) also supports this in relation to identification of children with hearing impairments and would support the idea that highly technical identification procedures should be replaced by more simple low cost procedures, until appropriate intervention and more technical backup is available.

### **Should play be introduced as a vehicle of learning where this is a cultural anathema? If so why and how can this be done effectively?**

Play forms a corner stone of therapeutic intervention in our culture, but many cultures reject the role and value of play as a learning process and this makes it difficult to introduce it as a vehicle for learning. If play is not considered a culturally acceptable process what should take its place? Who has expertise in this alternative?

The researcher observed that sometimes the cultural issue was a linguistic one and when the word 'play' was dropped and re-presented as 'work' or 'experience' then it became more acceptable.

Finally, is improved service delivery the way forward at all? Is it too patronizing or does it imply superior knowledge? Perhaps it would be healthier to work towards pragmatic meaningful partnership which would enable and empower all involved?

**To summarize the questions which should be considered by service providers:**

- \* Who will take the co-ordinating role in providing these services?**
- \* Who will be the key worker with the person with communication disabilities?**
- \* Will/does the training of this key worker include an appreciation of the overall situation?**
- \* Is it better (or possible) for the potential key worker to have knowledge and skills in all the areas which affect the communication functioning levels?**
- \* Or is it better (or possible) for them to specialize in one area and recognize their own limitations?**
- \* What is the role of the person with the communication disability, their family, the speech and language therapist, the teacher, the doctor and the community worker, within this model?**
- \* Is integration of the factors affecting communication functioning possible if the different aspects of it are dealt with by a variety of professionals?**
- \* Is the defense of professional 'standards' and technical territory carried out at the cost of ignoring the importance of social and environmental factors influencing the effectiveness of service delivery?**
- \* What are the roles of funders and aid agencies?**



### 6.6.0. APPLICATION OF THE 'COMMUNICATION DISABILITY MODEL' TO INDIVIDUAL INTERVENTION.

Interventions based on impairment related categories form the basis for the present state of the art in speech and language therapy (Van der Gaag 1996), but in countries where there are very few, if any, services of this kind, with very small numbers of people who have the background and expertise to develop such a service, this highly specialized approach is not a practical option, except for the few elite.

Supporters of impairment based services might argue that effective intervention cannot be carried out without detailed knowledge of the impairment, as intervention is based on this knowledge, however the researcher would argue that:

1. The impairment based intervention is only part of the intervention and omits the three other elements identified in the study.
2. A number of interventions are beneficial to all children with communication disabilities.

e.g.. - hearing test

- including the child in daily activities
- communicating with the child through best available mode
- establishing the importance of turn taking
- improving listening and attention skills
- understanding the person's need to communicate
- need for family involvement and understanding.
- need for long term input.
- talking clearly and normally

In support of point number 1 above, the data collected in Nigeria and Uganda shows that services based on meeting needs identify impairment as one of **four** areas that require attention, so intervention based on the communication disability model has a broader base than a specialized impairment related approach. It gives emphasis to the importance

of the other elements of the model and opens the possibility for more involvement of community workers, parents, family members and communities. Interventions targeting the social factors of the disability might be tackled better by the people and the families themselves through parent support groups, child-to-child programmes and self help groups. Such interventions do not require technical knowledge of, for instance, phonetics and linguistics, but may need the encouragement and facilitation skills of an advocate or promoter of services. Likewise environmental factors affecting this disability are best tackled by the community, but as such they may require the encouragement and support of professionals to succeed.

So interventions at a community level by community level workers open up the possibility of implementation of simple basis principles which may have considerable impact on the disability level of the person concerned, and do not require highly technical skills. For instance, an intervention based on persuading families to include their child as part of the family, to talk to him regardless of his lack of response, to include him when guests visit and to take him on expeditions as an opportunity for experience, are likely to have a greater impact than the best prepared technical therapy sessions on a weekly or bi-weekly basis.

At an individual level it is easy to see that application of the model to assessment would form the basis for collecting information which will show different proportions of the different issues involved, thus it allows for individual variation and encourages exploration and consideration of the four areas of need which have been identified in this study.

Using some of the children seen in Survey 3 in Uganda, BB of Lubido reported to have had polio which had affected his mobility also had some paralysis of the speech musculature and delayed speech development. His 'impairment' would be seen as the polio and whatever had affected control of his speech musculature also the possibility of mental impairment delaying his speech development. His range of functioning could be assessed in relation to his impairments and also his social and environmental situation. His social and cultural



circumstances revealed a humble remote rural African existence with a supportive family and community. His range of functioning was limited as much by his environment and social circumstances as by his impairments, because of his immobility he would probably be unable to attend school which was several miles walk from his compound. At an impairment level medical intervention was unlikely to have any impact and impairment related therapeutic intervention might include 'exercises' for his speech musculature which would probably be of limited benefit. At a social and environmental level, increased understanding of his difficulties by the family and community might help him to be included in their daily lives in a more meaningful way. This would expose him to experience, ideas and feelings of other people and give him the opportunity to share his own contribution and create a greater feeling of self worth. The increased mobility achieved by the use of the parallel bars allowed him to see more of what was happening around him and further adaptations of the compound would probably be able to assist him to move from place to place independently. Identification of areas of functioning which he could perform independently, e.g.. preparing food, watching smaller children, feeding chickens could assure him a useful place in his own society, be used as a basis for meaningful exposure to the possibilities of communication, and if progress were made the family could be supported through community services to help him to attend the local school.

A second example of R., also of Lubido, revealed a young women with pre-lingual sensori-neural hearing impairment, she had married and been returned home as 'unsatisfactory'. At an impairment level, surgical intervention was unlikely to be of benefit and amplification impractical and inappropriate in this remote and poor community. Again the impairment was undoubtedly affecting the ability to communicate but equally the cultural expectation of the society from which she came had devastating consequences. Support from community workers to establish some communication skill through signing with encouragement and fellowship from other families with deaf members, might be a more realistic and meaningful intervention. It would be of low cost and in comparison with impairment related intervention would require less skilled workers and would probably be more appropriate to the young women's needs.



### 6.7.0. APPLICATION OF THE COMMUNICATION DISABILITY MODEL TO TRAINING.

The questions are asked: 'How can intervention based on this model develop? How can the skills of the various people required be developed to meet these identified needs?'

The data collected in this study suggests that new services must look to becoming part of the structure which already exists, whatever that might be. There is an identified need to change the attitudes and the methods used within those structures and one of the ways that this can be done is through the development of appropriate training.

If training continues to be based on either medical interventions or social interventions with limited realization of the importance of the interaction between the two, this is an unachievable goal. The proposed model allows for consideration of the two perspectives together, and if used as a basis for training would suggest that an important role could be played by professionals in training community workers in health, education and social services, to increase their knowledge and skills to help people with communication disabilities.

Recent exploratory research, described in a personal communication, conducted by Sarah Rule, a Speech Therapist in South Africa at the Institute of Urban Primary Health Care, Wynberg is directly concerned with looking at the difficulties of providing appropriate training for Community workers in Communication disabilities and indicates some interesting areas for consideration. One was that the CBR workers complained of difficulty in actually communicating with their clients, maybe due to unintelligible speech due to dysarthria, or not having the ability to use sign language. They reported a lack of skills relating to helping this type of client and discouragement from observing a lack of progress. The difficulties of this client group contributing to, or being part of, the disability movement are possibly self evident, but significant in terms of representation and understanding of their interests.



**Based on the 'communication disability model' the objectives of such training might be:**

Development of practical skills which would include:

- \* Ability to identify a variety of communication disabilities.
- \* Ability to carry out basic and appropriate screening procedures.
- \* Ability to provide basic interventions strategies.
- \* Ability to provide support and information to the family and community.
- \* Ability to make appropriate referral to other services.

**The course content might include:**

- \* Knowledge and understanding of the concept of communication disability as developed and described in this study.
- \* Knowledge and understanding of the different modes of communication as shown in the visualization of communication disability.
  - talking
  - understanding
  - signing
  - body language and gesture
  - reading and writing.
- \* Knowledge of the impairment categories associated with communication disability and the prevention strategies.
- \* Observation and assessment skills related to the local service options.
- \* Normal development of communication skills.
- \* Recognition of the parent and families role and the skills to facilitate their involvement
- \* Evaluation and record keeping relating to people with communication disabilities.
- \* Ability to identify needs and develop strategies to meet the identified needs.

- \* Awareness and understanding of local culture and services.
- \* Awareness of cultural and environmental aspects which can be changed and those which cannot be changed.
- \* Knowledge and skill in basic interventions possible at community and home level which facilitate the development of communication skills.  
e.g. Talk to your child when you are together.  
Encourage your child to listen and identify different sounds.  
Encourage your child to communicate in any way, not just through words.
- \* Appreciation of the importance of interaction to the development of self identity/ awareness/acceptance.
- \* Information on technical aids locally available.
- \* Understanding and management of difficult behaviour relating to communication disabilities.
- \* Rights of disabled people and how these relate to people with communication disabilities.
- \* Acceptance of their own personal limitations.

In order to achieve training of this kind specialists in communication, such as speech and language therapists, would need an appreciation of the holistic approach and of the place and relative importance of speech in relation to overall communication skills. Education of speech and language therapists and other specialists would need to include the motivation and skill to share knowledge with other workers, perhaps giving more emphasis on negotiating and counselling and less on individual therapeutic interventions.

It is reassuring to note that there are many similarities between these recommendations for training and those made by Bortz et al (1996) based on their experiences of training personnel for what they call 'an alternative form of service' using community speech and hearing workers and community rehabilitation workers. This training has developed in response to overwhelming need and an awareness of the need for contextual sensitivity. They have not however moved far from the 'disorder' base, but have recognised and included important areas such as prevention and detailed the issues around primary health care and empowerment.



**In conclusion the researcher would like to suggest that the term 'People with Communication Disability' be adopted in all related literature in order to:**

- \* indicate appreciation and understanding of the different components involved and to move away from understandings dominated by an impairment based perception. (e.g. communication 'disorder')**
- \* develop integrated services which recognize and tackle all the components of communication disability including the recognition of the role of the person with the disability and the family and use this as a basis for service delivery and training.**
- \* to do this by utilizing the existing social structures.**

### 6.8.0. SUGGESTIONS FOR FURTHER RESEARCH.

- \* Exploration of the ingredients of the environmental and social factors which contribute or detract from children's communication ability, based on contextually appropriate standards.
- \* Investigations into the reasons for the gap between theoretical knowledge and practical application of that knowledge.
  - e.g. CBR techniques - implementation
  - Special Education- implementation of inclusion
  - Institutions vs. Community based services.
- \* Are there different attitudes towards people with communication disabilities in cultures with a high versus low regard for oralism?
- \* What are the implications of the lack of archival tradition on the development and sustainability of services for people with communication disabilities in LDCs?
- \* Is "service delivery" the right approach or is it too patronizing? Does it imply a superior more knowledgeable being and a receiver? How can we implement service which works towards partnership, enabling and empowerment?
- \* Development of process indicators which are cultural appropriate and their relationship to people with communication disabilities and the services provided for them.
- \* Is inclusion a practical option for children with severe communication disabilities or is the ability to communicate a pre-requisite to the inclusive approach?
- \* What is the relationship between full citizenship and level of communication ability?



- \* In what way do people's communication functions alter when interacting with a person with communication disabilities, how does this impact upon the person with the disability?
- \* What is the role of communication in the user service interface of Primary Health care in LDCs? How does the communication ability of health professionals impact on the efficacy of the service or intervention?
- \* The use of drama/role play as a communication avenue which could be utilized to change attitudes and gain knowledge about people with disabilities.
- \* Given that difficulty in communicating is often secondary to an underlying impairment there is a need to gather more information from the people affected, about what they consider to be the primary disability and look at how this impacts on intervention strategies.
- \* What is the role of the Grandparent in fostering the development of their grandchildren's communication ability and how can this be utilized?
- \* Data should be collected on the impact of impairment-led interventions for people with communication disabilities concentrating on differential diagnosis and individual change, and compared with interventions concentrating on:
  - improving communication opportunity
  - improving family support
  - improving community knowledge and attitudes, and measured in terms of:
    - communication skills
    - identity within the family
    - identity within the community.

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## APPENDICES

### APPENDIX 1.

**A summary of the essential issues covered by “The National Health policy and Philosophy to achieve health for all Nigerians.” Federal Ministry of Health, Lagos, October 1988.**

1. The Federal Government is committed to providing comprehensive coverage of health care for all its citizens, with primary health care serving as the main thrust of implementation. The Federal Government takes responsibility for policy guidance and support to the States. It also takes responsibility for monitoring and evaluation of its implementation. All the Governments agree to work together to achieve this aim.
2. The health services of Nigeria have evolved through a series of historical developments including a succession of policies and plans which have been introduced by previous administrations. The health services are judged to be unsatisfactory and inadequate in meeting the needs and demands of the public as reflected by the low state of the health of the population.
3. This National Health Policy, to achieve health for all Nigerians, is based on the National philosophy of social justice and equity. A health system based on primary health care is adopted as a means of achieving this goal.
4. The goal of the national health policy shall be a level of health that will enable all Nigerians to achieve socially and economically productive lives. The National Health systems will be based on primary health care.
5. Federal, State and Local Government shall support in a co-ordinated manner a three-tier system of health care. Essential features of the system shall be its comprehensive nature, multisectoral inputs, community involvement and collaboration with non-governmental providers of health care.
6. The implementation of this national health policy, and progress towards the achievements of the goals, require the elaboration of strategies at the local state and national levels. The roles of the different arms of government shall be defined from time to time. A managerial process for health development will be established.



**7.** It is generally recognized that a more effective delivery of health care can be achieved in this country by a more efficient management of health resources. Experiences have shown repeatedly that many well conceived health schemes fail to meet expectations because of failures in implementation. It is essential to establish permanent systematic managerial processes to establish permanent, systematic managerial processes for health development at all levels of care. These shall include appropriate control to ensure the continuity of the managerial process from design to application.

**8.** The effective management of health service demands the establishment of a national health information system. Basic demographic data are essential for planning and monitoring of health services. Simple but efficient information systems shall be established and supported to grow both in quality and quantity.

**9.** Ministries of Health shall ensure that medical, nursing, public health and other schools of health sciences under their jurisdiction include in their education programmes the philosophy of 'Health for all' the principles of primary health care, and the essentials of managerial process for National Health development, and to provide appropriate, practical training in these areas. In a similar manner efforts shall be made to involve technical workers in other sectors having a bearing on health. The selection, training and development of health, manpower, shall reflect the national objectives with particular emphasis of the primary health care approach. Appropriate policies shall be evolved to secure a more equitable distribution of health personnel throughout the country.

**10.** The most appropriate health technologies shall be selected for use at all levels of the health care system. Particular care shall be taken to identify the most cost effective technologies and to maintain them at the highest level of efficiency. In order to reduce the importation of supplies, indigenous manufacturing capabilities shall be fostered in the spirit of self-reliance.

## **APPENDIX 2. PROFESSIONAL ORGANIZATIONS IN NIGERIA.**

### **THE NIGERIAN SPEECH AND HEARING ASSOCIATION.**

This association was set up in 1985 and is a professional Association for 'Audiologists, Speech pathologists audiometricians and speech therapists. It does not clarify the difference between these groups but only offers full membership to such persons who have a Bachelors Degree or equivalent with specialization in speech Pathology and Audiology. Associate membership is open to allied professions such as psychologists, Otolaryngologists, Councilors and Social Workers. Annual membership is N100 per annum (at the current rate of exchange this is just over £3.) It is the intention of the Association to publish a journal, but so far this has not come to fruition. However they did organize the first conference last year, with speakers from all over the country contributing. There were about 30 members in attendance.

### **THE NATIONAL ASSOCIATION OF SOCIAL WORKERS. (NASOW)**

This Association was established in the 1960's, each State has its own branch, including both Oyo and Osun States. It is a large organization with over a thousand members, Medical and Prison Social Workers are included although they do have their own separate professional bodies. The Oyo State Branch has meetings every month where professional issues are discussed. The Association also offers professional support by means of lectures and workshops.

### **THE NIGERIAN ASSOCIATION OF OCCUPATIONAL THERAPISTS.**

This Association has a constitution stating its aims and rules of membership, and has been formed to promote and protect its members. There are currently 50 members in the country all of whom have been trained overseas.. Salaries are paid in line with rate recommended on the paramedical scale. Meetings are held regularly, usually in Lagos. Occupational Therapists are one of the member professions included by the Medical Rehabilitation Registration Decree of 1988, whereby they are required to register and their standards of practice will be regulated and monitored. Implementation of this decree has yet to be put into effect.



### **THE NIGERIAN ASSOCIATION OF PSYCHOLOGY.**

This Society is for professional people who are interested in and have studied Psychology. Most of its members are teachers and very few, if any practice clinical psychology.

### **THE NIGERIAN ASSOCIATION OF SPECIAL EDUCATORS.**

This has a reputation as a strong professional body with many members from the lecturing staff of the Special Education departments of Federal Colleges and Universities.

### **NIGERIAN SOCIETY OF PHYSIOTHERAPISTS.**

The Society was established in the 1970's and now has 500+ members. There are State Branches of the Society some more thriving than others. The state branch for old Oyo State has not so far divided into two state branches and has c35 members. It meets regularly on a monthly sometimes bimonthly basis. It has a constitution outlining its aims and purposes etc. Membership is only open to those who hold recognized qualifications in physiotherapy and the constitution aims to protect and promote their interests and the interests of their patients.

### APPENDIX 3. CHECK LIST OF QUESTIONS FOR KEY INFORMANTS INTERVIEWS .

1. How did you become involved with people who have communication disorders?
2. How do you visualize services for people with communication disorders developing in Nigeria?
3. What do you feel are the urgent issues?
4. Do they have a word for disabled people in your local language?  
for the deaf? Blind? Physically handicapped? Mentally handicapped? “dumb”? Do these words have other meanings?
5. What are the traditional beliefs held about these categories of people as far as you know?
6. Whose fault is it when someone is disabled?
7. What are your key cultural principles? How do they affect disabled people with communication disorders.
8. How do people in society obtain rank or high standing? Inheritance, gender? wealth, Land personal ability, experience, education.
9. Is this affected by disability? Is it more affected by certain kinds of disability?
- 10 Is a person to blame for his disability?
11. Are people with disabilities punished by society or law?
12. If someone cannot talk properly where do you think he or she should look for help? Health Centre? Hospital? Traditional Healer? Medicine? Family support, community support?
13. Given that most people cannot get help from the services that are offered, what do they do? Where do they go for help?



#### APPENDIX 4. CHECK LIST OF QUESTIONS FOR GROUP DISCUSSION .

1. What are your traditional beliefs about people/ children who cannot speak and communicate?
2. Do you think people who cannot communicate should be educated formally or trained to be useful in the community?
3. What attitudes do you and your family have to people who are disabled?
4. In what way does the fact that your child has a handicap make a difference to the way you treat him? Do you send all your children to school?
5. What has been most helpful to you in dealing with the difficulties that arise from having a child who is disabled?
6. What role should the family/ community play in the care of the disabled?
7. How do you feel about your disabled child? Guilty? Sad? Cross?
8. How does having a person in the family who cannot communicate easily, affect your daily life?
9. As parents of children with special needs, what do you think they need most?

## APPENDIX 5 SURVEY 1A & B WITH NIGERIAN STUDENTS & PROFESSIONALS

Name

Age:

Home Area:

Ethic Group:

## Subject of study

Please list the following communication disorders in order of severity, starting with the one you consider will result in the greatest disability and ending with the one that in your opinion has the least effect on peoples lives.

**Head Injury or Stroke.**

**Mental Handicap.**

## Voice Disorders

Pre-school children who cannot talk.

**Cerebral Palsy.** ( brain damage causing physical disabilities)

**Degenerative Disorders.** (damage to the nervous system which becomes worse as time passes.)

## Stammering.

Cleft Palate.( A hole in the palate)

## Deafness.

School children who do not speak or understand properly. (not deaf or MH)

List them in order 1-10 starting with the most disabled and ending with the least disabled. In other words grade them according to the amount of human suffering they are likely to experience and the effect this will have on their relationships with family and friends

1.

2.

3.

4

5.

6.

7.

8.

9.

10.



The following descriptions should be ranked according to what degree of disability you feel the person would be suffering from. Please circle the appropriate number in the box below each question.

- 0. - No disability.
- 1. - Slight disability.
- 2. - Slight/Moderate disability.
- 3. - Moderate disability.
- 4. - Severe disability.
- 5. - Very severe disability.

1. A three year old boy who is mentally handicapped and cannot understand or speak at all, even with his family.

0	1	2	3	4	5
---	---	---	---	---	---

2. A six year old girl who is moderately deaf whose speech cannot be understood outside the home.

0	1	2	3	4	5
---	---	---	---	---	---

3. A 40 year old man who has had a stroke and now cannot understand most of what is said to him.

0	1	2	3	4	5
---	---	---	---	---	---

4. A 15 year old girl who has an unoperated cleft-palate. She has problems talking clearly, but has learnt to read and write and communicate with signs.

0	1	2	3	4	5
---	---	---	---	---	---

5. A 54 year old mentally handicapped woman who is able to use a few words to express her basic wants and needs.

0	1	2	3	4	5
---	---	---	---	---	---

6. A deaf man of 30 who is totally deaf. He can communicate with signs to his family and friends.

0	1	2	3	4	5
---	---	---	---	---	---

7. A six year old boy just starting school whose speech is not clear. He cannot be understood by his teacher and friends.

0	1	2	3	4	5
---	---	---	---	---	---

8. A 10 year old cerebral palsied girl who stays at home. She talks very slowly and draws out her words. She understands what is said to her.

0	1	2	3	4	5
---	---	---	---	---	---

9. A man of 41 has had his voice box removed so he cannot speak at all. He can understand everything that is said to him.

0	1	2	3	4	5
---	---	---	---	---	---

10. A lady teacher of 8 develops a very sore throat that will not go away. She cannot talk because she has lost her voice.

0	1	2	3	4	5
---	---	---	---	---	---

11. A 14 year old girl has had a car accident, she hurt her head and now although she speaks clearly, what she says does not make sense. She does not understand what is said to her.

0	1	2	3	4	5
---	---	---	---	---	---

12. A 3 year old boy seems OK in every way except that he is not speaking at all. He seems to understand what people say to him.

0	1	2	3	4	5
---	---	---	---	---	---

13. A man of 46 seems to be losing the ability to control his muscles. He understands everything that is said to him. His own speech is becoming slurred and he is sometimes difficult to understand.

0	1	2	3	4	5
---	---	---	---	---	---



14. A boy of 11 does not dare to stand up at school to read to his class because his stammer is so bad he feels very embarrassed.

0	1	2	3	4	5
---	---	---	---	---	---

15. A woman of 35 cannot speak clearly any longer due to an illness that has been getting worse for a number of years. She understands what is said to her, but although she can read, her writing is very poor and difficult to follow.

0	1	2	3	4	5
---	---	---	---	---	---

16. A 20 year old young woman never talks or joins in conversations with strangers . Her stammer is so bad when she talks to her family and friends she hardly ever communicates with them.

0	1	2	3	4	5
---	---	---	---	---	---

17. An 18 year old young man has had cerebral palsy since he was born, he cannot walk and sits at home all day. He cannot speak or understand but grunts and gestures to make his wants known.

0	1	2	3	4	5
---	---	---	---	---	---

18. A four year old child who talks a lot but all her sounds are muddled up and even her mother has difficulty understanding what she says.

0	1	2	3	4	5
---	---	---	---	---	---

19. A twenty five year old man has a cleft palate and hare lip. The palate and lip were operated on when he was seventeen. He looks different from other people and cannot speak clearly enough to be understood by strangers. He can understand everything that is said to him.

0	1	2	3	4	5
---	---	---	---	---	---

20. A twelve year old girl is having a lot of problems at school because she cannot remember the names of things. When she speaks or writes she only uses a very few words and often gets them in the wrong order. She is doing badly at school because of this.

0	1	2	3	4	5
---	---	---	---	---	---

**APPENDIX 6. SURVEY 2 QUESTIONNAIRE WITH NIGERIAN PARENTS.**

**1. What is your relationship to the person who cannot talk properly?**

- |          |                        |
|----------|------------------------|
| Mother ? | Father?                |
| Aunty ?  | Sister?                |
| Uncle ?  | Other, please specify. |
| Brother? |                        |

**2. How long has this person (XXX) not been able to speak properly?**

- |                 |                      |
|-----------------|----------------------|
| 1 year or less. | 2 years              |
| 3 years         | 4 years              |
| 5 years plus    | All his or her life. |

**3. Where has XXX been taken to for help?**

- |                                       |                                  |
|---------------------------------------|----------------------------------|
| Health clinic? Private? State? Yes/No | Hospital? Private/ State? Yes/No |
| Traditional Healer? Yes/No            | School? Yes/No                   |
| Other? Yes/No Explain.                |                                  |

**4. How many times has XXX been to the places below for help for his difficulty with talking?**

- |                                  |   |    |    |    |    |                 |
|----------------------------------|---|----|----|----|----|-----------------|
| The Health Clinic?               | 1.  | 2. | 3. | 4. | 5. | More than five  |
| The Hospital?                    | 1   | 2  | 3  | 4  | 5  | More than five. |
| The Traditional Healer?          | 1   | 2  | 3  | 4  | 5  | More than five. |
| The School? To visit for advice? | 1   | 2  | 3  | 4  | 5  | More than five. |
| To attend for special help?      | 1 term 2 terms 3 term<br>2 years 3 years 4 years. More. |    |    |    |    |                 |

**5. How far did you have to travel from home to make these visits?**

- |                        |           |        |         |       |
|------------------------|-----------|--------|---------|-------|
| For the Health clinic? | Under 5km | 5-10km | 10-50km | 50km+ |
| For the Hospital?      | Under 5km | 5-10km | 10-50km | 50km+ |
| For the Trad. Healer?  | Under 5km | 5-10km | 10-50km | 50km+ |
| For the School?        | Under 5km | 5-10km | 10-50km | 50km+ |



**6. What form of transport did you use?**

Health Clinic?	walk	bike	bus	taxi	private car?
Hospital?	walk	bike	bus	taxi	private car?
Trad. Healer?	walk	bike	bus	taxi	private car?
School?	walk	bike	bus	taxi	private car?

**7. How much did it cost for one return journey?**

Health clinic?	Nothing	Under 5N	10-20N	50-100N	More
Hospital?	Nothing	Under 5N	10-20N	50-100N	More
Trad. Healer?	Nothing	Under 5N	10-20N	50-100N	More
School?	Nothing	Under5N	10-20N	50-100N	More

**8. Who did you see at**

Health clinic?	Doctor	Nurse	Health Worker	Other (specify)	
Hospital?	Doctor	Nurse	Health worker	Therapist	Other(specify)
Traditional Healer?	Spiritualist	Herbalist	Healers	Other (specify)	
School?	Head teacher	teacher	specialist	Other(specify)	

**9. What did it cost per session or per term?**

Health Clinic?	10 N or under	50N	100N	200N	500N
Hospital?	10 N or under	50N	100N	200N	500N
Traditional Healer?	10N or under	50N	100N	200N	500N
School?	10N or under	50N	100N	200N	500N

**10. What treatment/help did they give you?**

Health Clinic?	Advice	Medicine	Onward referral	
Hospital?	Advice	Medicine	Therapy	Operation Onward referral
Traditional Healer?	Advice	Medicine/ herbs	Rituals	Other please specify.
School?	Advice to carers	Teaching Child	Other please specify.	

**11. Have you given XXX any drugs or medicine to help make him talk better? Yes / No**

**12. How many times?**      1    2    3    4    5    6    7    8    9    10    more

**13. Was it helpful? Please grade the amount of help you think you received from your visits to the places listed. 0 is no help at all, 1 is a small amount of help, through to 5 which is a great deal of help and benefit.**

Health Clinic?	0	1	2	3	4	5
Hospital ?	0	1	2	3	4	5
Traditional Healer	0	1	2	3	4	5
School?	0	1	2	3	4	5

**14. Can you name any of the medicine you used?**

**15. Which of these services did you go to first, which second etc.**

Health Clinic	1st.	2nd.	3rd	4th.
Hospital	1st.	2nd	3rd.	4th
Traditional Healer	1st	2nd	3rd	4th
School	1st.	2nd.	3rd	4th

**16. Who helps you look after XXX?**

Grandmother    Aunty    younger brother/sister    friend etc.    please name

**17. What wants and needs does XXX have that are different from people who can speak properly?**

**18. Does the community help look after XXX?    yes / No**

**In what way does it help?**

**19    What do you think will happen to XXX when he/she is grown up?**

**What will he/she be able to do?    Where will he/she live?**

**20    What could be done to make his/her life better?**

Thank you **very** much for your help.



**APPENDIX 7a. CDA's FROM MBALE DISTRICT IN ALPHABETICAL ORDER OF THE FIRST NAME LISTED ON THE ATTENDANCE SHEET.**

\* Every fourth CDA was selected for the monitoring process and is marked with a\*

Each of these CDA's was visited individually and checks made on their understanding of the questionnaire. Additionally a completed questionnaire was selected at random and the case visited. A repeat questionnaire was then completed for monitoring purposes.

Abol Francis	- Muyembe sub-county
Alex Mubaggee	- Greenfields Disabled Association.
Josephine Nafuma	- Mbale Disabled Women's Association
*Khankha Johny *	- Buhugu s/c
Kuloba Samuel	- Bugobero s/c
Kyeune Patrick	- Nabumali Vocational Inst. for the Blind
Lulonde Faith	- Bupoto s/c
*Mabala Wambalo *	- Bushikha s/c
Maena Sarah	- Bulamuli Peoples Projects
Mumali Nicholas	- Buwabwala s/c
Nakedi John	- Buwalasi s/c
*Namawa Paul *	- Sisiyi s/c
Ojambo Joseph	- DRO Mbale
Sinuyi Bogere	- Bududa s/c
Wakwabubi Nalbau	- Busiu
*Wamoto David *	- Bulucheke s/c
Wamukota Lawrence	- Bukhiende s/c
Weswa Richard	- Bubiita s/c
Weyusya Joseph	- Bumbo s/c

# APPENDIX 7b. CDAs FROM TORORO DISTRICT, IN ALPHABETICAL ORDER BY THE FIRST NAME LISTED ON THE ATTENDANCE SHEET.

\*Every fourth CDA was selected for the monitoring process and is marked with a \*

Each of these CDA's was visited individually and checks made on their understanding of the questionnaire. Additionally a completed questionnaire was selected at random and the case visited. A repeat questionnaire was then completed for monitoring purposes.

Mr. Adongo R.	- Muwinda sub - county
Angelo Mayamba	- Lwebonge sub-county
Mrs. Bwire T.M.K.	- DRO Tororo Town
*Mr. Dakkar F.*	- Buteleja sub-county
Donosin Ekirapa	- Molo sub-county
Ilukor Paul	- Molo sub-county
Kevina Nafuna	- Masafu sub-county
*Mugoto Emmy Charles *	- Masaba Disabled Association (NGO)
Nanderu Bibiana	- Kachongoi sub-county
Nantambaw	- Bulumbi sub-county
Nali Edim	- Busaba sub-county
*Oguti Richard *	- Kwapa sub-county
Okowugo	-
Onyango Henry	- Lumino Disabled Association (NGO)
Onyango Jerome	- Kisoko sub-county
*Onyango John *	- Kibrewa sub-county
Opendi Nicanor	- Mwanda disabled Association (NGO)
Osamai James	- Paya sub-county
Ouchuna	- Butebe sub-county
*Wanderu Geoffrey *	- Tororo Association for the Disabled (NGO)



## APPENDIX 7c. CDAs FROM IGANGA DISTRICT WHO RECEIVED THE QUESTIONNAIRE IN ALPHABETICAL ORDER OF THE FIRST NAME GIVEN.

\*Every fourth CDA was selected for the monitoring process and is marked with a \*

Each of these CDA's was visited individually and checks made on their understanding of the questionnaire. Additionally a completed questionnaire was selected at random and the case visited. A repeat questionnaire was then completed for monitoring purposes.

Baligwanunsi H.	- Ikumbya sub-county
Balukuba R.	- (NGO)
Bridget Maleka	- Baitabogwe sub-county
*David Kateteyi *	- Bugwere Disabled persons Association
Ferdinand Wandera	- Buinja sub- county
Mrs. Isabinye	- Bukoma sub-county
Jessica Tulibona	- Namalembe sub-county
*Kiirya Ngobi Sam *	- (NGO)
Mr. Kiyuba	- (NGO)
Mr. Lubale Martin	- Nawampiti sub-county
Mrs Magala	- Kapanga sub-county
*Mr. Mpiiya Stephen *	- Magonda sub-county
Mugerwa George	- Iganga Town Council
Namukinma M. Gorelli	- Bulamagi sub-county
Mr. B. F. Obbo	- Muyingo sub-county
*Opio Joseph *	- Namungalwe sub-county
Sanyu Paul	- Namutumba sub-county
Sarah Tugonzo	- Makutu sub-county
Walukoba Herbert	- Kituerera sub-county

APPENDIX 8 MODIFIED QUESTIONNAIRE FOR SURVEY 3.

QUESTIONNAIRE 3. DATA NO.....

THIS QUESTIONNAIRE SHOULD BE USED ON ALL THE CHILDREN (0-18) YOU SEE FOR YOUR HELP AND ASSESSMENT DURING JANUARY AND FEBRUARY 1995.

Date of assessment .....

Name of Community worker.....Sex.....Area.....

Name of child.....Sex.....Age.....

Child accompanied by: Mother, Father, Sister/Brother, Uncle / Aunt, friend, other. Please circle or tick where appropriate.

Child's address.....

Village.....Area.....

Please circle or tick the type of difficulties this child appears to have :-

Physical impairment,

Mental / Intellectual impairment,

Visual impairment

Hearing impairment.

Emotional / Behavioural impairment



DATA NO.....

PLEASE ANSWER THE FOLLOWING QUESTIONS BY MAKING YOUR OWN OBSERVATIONS AND / OR BY ASKING THE CARER FOR THEIR REPORT.

Circle the correct responses to each of the following 10 questions.  
Consider each question twice over.

- 1. From the point of view of your own observations then answer the question OBSERVED - YES or NO.
- 2. From information that has been reported to you by the Mother or family, answer RE-PORTED - YES / NO.

ASK ALL CHILDREN THE FIRST 7 QUESTIONS.

- |  |  |
|--|--|
| 1. Does the child appear to have difficulty hearing?   | OBSERVED - YES / NO<br>REPORTED - YES / NO |
| 2. When you tell the child to do something does s/he seem to understand what you are saying? | OBSERVED - YES / NO<br>REPORTED - YES / NO |
| 3. Does the child speak at all?  | OBSERVED - YES / NO<br>REPORTED - YES / NO |
| 4. Can s/he make himself/herself understood in words?  | OBSERVED - YES / NO<br>REPORTED - YES / NO |
| 5. Can s/he say any recognizable words?  | OBSERVED - YES / NO<br>REPORTED - YES / NO |
| 6. Does the child have any difficulty eating and chewing his/her food?                       | OBSERVED - YES / NO<br>REPORTED - YES / NO |
| 7. Does s/he slaver or dribble?  | OBSERVED - YES / NO<br>REPORTED - YES / NO |

ASK THIS QUESTION FOR CHILDREN 2 YEARS AND UNDER.

- |  |                     |
|--|---------------------|
| 8. Can s/he name at least one object or thing? e.g.. | OBSERVED - YES / NO |
| a person an animal, a toy, food or drink?            | REPORTED - YES / NO |

ASK THESE QUESTIONS FOR CHILDREN BETWEEN 3 & 18 YEARS OLD.

- |  |   |
|--|---|
| 9. Is the child's speech in anyway different from other children the same age?                     | OBSERVED - YES / NO<br>REPORTED - YES / NO  |
| 10. Is the child's speech clear enough to be understood by people other than his immediate family? | OBSERVED - YES / NO<br>REPORTED - YES / NO. |

## APPENDIX 9. MEMO TO CDOs.

To : Community Rehabilitation Officers, Mbale, Tororo and Iganga.

From: Mrs. Sally Hartley. Institute of Child Health, London.

Subject: Survey on Communication Disability

Date: 29.1.96.

On checking through some of the completed questionnaire forms, it seems that there is a need for each form to be checked by the CRO when they are handed in by the CDA's. I suggest that the CRO sits down with each CDA and checks each form individually as the are handed in, this can also be used as an opportunity to discuss the case in question and the action that the CDA is taking to help the family and community cope with the situation.

The following points need checking on EACH and EVERY form.

1. Are the particulars on the front of the form correct and complete?
2. Have both the OBSERVED AND REPORTED answers been recorded, if not, is this because the information was not gathered, which is quite OK, or is it because the CDA has forgotten to fill it in?
3. Have the last two questions been filled in for ALL the cases over 3 years old, if not can they be completed please?
4. Is the ticking and circling clear?
5. Are the answers to the questions compatible?  
     e.g.. Does the child speak at all? NO  
         Can the child make himself understood in words YES

THESE ANSWERS ARE NOT COMPATIBLE!!

AT THE END OF THE EXERCISE ALL THE FORMS SHOULD BE RETURNED, BOTH ONES COMPLETED AND THE ONES THAT HAVE NOT BEEN USED. CAN THE CRO CHECK THIS WITH EACH CDA PLEASE?

The forms collected from the CDA's who were visited by myself appear to be satisfactory, but I am returning the forms belonging to other CDA's and would be very grateful if these could be checked.

I would be grateful if ALL the forms from Mbale district could be handed in to Regina Ssali as soon as possible and ALL the Iganga and Tororo forms returned to Regina BY 3rd. MARCH at the latest. With many thanks for your continued help and support.

cc. Mrs. Regina Ssali



## APPENDIX 10a. THANK YOU LETTERS TO CDA's VISITED DURING THE RESEARCH.

I would like to take this opportunity to thank you most sincerely for all your hard work and co-operation over the past three months concerning the collection of data about children with a communication disability. I really appreciate your input, without you we could not have been able to carry out this research. I am hoping that the results will help us to develop better strategies for such children and increase the awareness of the size and importance of this disability area. I will make sure that your department receives a copy of the analysis of the results as soon as it is completed.

I really enjoyed my visit to your area, thank you for your time and hospitality, I enclose some copies of photos I took while I was with you. Perhaps you would be kind enough to pass them on to the people concerned with my thanks to them for their co-operation? Thank you.

I have given your DRO and CDO a copy of "Disabled Village Children" by David Werner, and "Hearing and communication disorders" by Sheila Wirz and Sandy Winyard, also some copies of pamphlets about hearing matters, listening understanding, play and sign language. These publications are for your use in appreciation of the work you have carried out and I hope you will find them helpful.

With every good wish to you and your family,  
Sincerely,

Mrs. Sally Hartley.

## APPENDIX 10b. THANK YOU LETTERS TO ALL OTHER CDA's

I would like to take this opportunity to thank you most sincerely for all your hard work and co-operation over the past three months concerning the collection of data about children with a communication disability. I really appreciate your input, without you we could not have been able to carry out this research. I am hoping that the results will help us to develop better strategies for such children and increase the awareness of the size and importance of this disability area. I will make sure that your department receives a copy of the analysis of the results as soon as it is completed.

I am sorry that I could not come to visit you but as I am sure you will appreciate it was not possible to include everybody in the itinerary.

I have given your DRO and CDO a copy of "Disabled Village Children" by David Werner, and "Hearing and communication disorders" by Sheila Wirz and Sandy Winyard, also some copies of pamphlets about hearing matters, listening understanding, play and sign language. These publications are for your use in appreciation of the work you have carried out and I hope you will find them helpful.

With every good wish to you and your family,  
Sincerely,

Mrs. Sally Hartley.



## APPENDIX 11. TRANSCRIPTIONS OF KEY INFORMANT INTERVIEWS

### APPENDIX 11a TRANSCRIPTION OF INTERVIEW WITH ADEFUNKE SABAGE ON 2nd. DECEMBER 1993.

**RESEARCHER:** Can you tell me something about yourself? Something about your life history? How did you come to be involved and what you did before you came here to run your own school?

**FUNKE:** When I was in high school I wanted to become a medical doctor But when I was in High school I had an experience... I had a friend that had meningitis, she went home and came back after 2 weeks and was completely deaf. At that time there weren't very many deaf programmes for people of her own type, and it was even difficult to get a hearing aid and get anything done, and to be sure of what could be done to help her, and many people didn't understand that the problem of deafness at that time. Even the teachers in the school were not happy with her, they thought that she was naughty, but sometimes she didn't hear what the instruction was... she'd do something else and then she was asked to do something. She went through a lot of problems. Even the parents at home were not very understanding. They often felt bad about it. In our Society people don't take kindly to handicap in the family. They would always ask her to go and stay in the room when visitors come.

**RESEARCHER:** In another room?

**FUNKE:** In another room. So that people wouldn't know that they have a child that's got a hearing problem. She went through all that and managed to finish her high school.. Eventually she had to go, she was admitted to Galludet University in America She went to America And since that time I had it in my mind that I usually helped her to copy notes and do some other things that she need to do.. That she couldn't do because of the hearing problem. I had in mind of getting involved with these kind of people that have this kind of problem. But I was thinking of doing it by going into medicine and eventually specialize in ENT. But after my higher school. ... in my school you had to go for counseling for deciding what profession you would like to go to. The professor that was counseling.. I told him what I would like to do and he was the one that actually said... Well you seem very convinced about this and I think you will do better if you don't go in for real medicine... do something between education and medicine. He introduced me to the idea of audiology and speech and special education. But at that time there weren't any programmes in Nigeria, so I had to I had to stay home from University that year He gave me some people to write to, some universities to write to get information and also I went to USAIS at that time and I got some information from there to some universities in the States.. in the US. So I .. Some of them sent me forms and I filled in and I got admission in about four of them and I decided on one that wasn't too expensive. So I went to the Special Education Department at the University of Minnesota, then I went to Temple University and I did Audiology eventually I went to Galludet University and did a Masters programme in Audiology also. It was after that I came back to Nigeria I had always had a mind of working with younger people... when I came back from Nigeria I had an idea that the government would appreciate the type of idea that I had. So when I started working at University College Hospital (UCH) I suggested that we had a pre-school programme, a parent programme, but to my surprise they said that you could not just have things like that, it has to be passed by the government to accommodate such ideas. But I kept on... I was working there as a clinical audiologist, testing and counseling. So I was always last to receive the parents, and they always brought their problems to my side. I was getting really overwhelmed with all these parents coming in and telling me they had nowhere to keep the children. Schools that were available wont take younger children, the government was not ready to get involved with pre-school programmes so eventually there was a women that came one day that pushed be into starting this programme. She broke down and she was crying and she brought the child and she said... Well she doesn't have any place to keep the child. She had started to take her to some of the existing programmes, but always having problems, and nobody understands the boy and schools always complaining that they



don't know how to handle him. So, after. now she doesn't have a house help, and the husband works in another town, she decided something had to be done. So then it was the following... about three months after. that we decided to set up a little family programme and a pre-school programme, and we started with about... the first day we were open we only had four children, some of the children I had seen at UCH came....

**RESEARCHER:** When was that how long ago?

**FUNKE:** That was in 1987. By the end of that month, started in August.. by the end of that month we had about 7 children, five of them were deaf and two of them had speech problem. Together with our own children we started a programme. People keep bringing, parents tell other parents....

**RESEARCHER:** How many children have you got now?

**FUNKE:** We've got about.. it fluctuates between 80 and 100, and you know when we were running the bus and picking the children we had more children ... but now we had to stop the transport system. It was too much so we had about 80 something children. We expected...

**RESEARCHER:** Now you are hoping to move the school to another site.. could you tell me a bit about that and what you envisage might happen?

**FUNKE:** Well we have looked around and the place we are using is a rented place and we can't accommodate as many children as need our services, and number two we find out that some people need boarding facilities. Actually we want to as much as possible, we won't allow... I mean we didn't want to start with boarding facilities.. my own idea is that these children should grow within their own family, that the family should get involved in the education and the nurturing of children that have problems, disabled children. Most of our programmes are run residential and find out that children are just left there and they never really get the loving care that they need from their family. For example we have some children in the secondary school and even some at university, when their parents want to discuss with some deaf adults. They will still have to come to me and ask me to interpret.

**RESEARCHER:** Is that because of sign language or because of the language, because they speak another language, because they have been taught in English?

**FUNKE:** Because of sign language and because these children, these one that are now adults have no legal along with the family, they had always been in residential programmes and so the kind of relationship they are supposed to have with their families is not there.

**RESEARCHER:** What about the language difficulties that develop when say children are educated in English and the family don't speak English?

**FUNKE:** We have that also, like parents who cannot speak English. We modify some of the signs sometimes, who have some words in English and the vernacular language. They can sign. We find out that because the children are not even at home the parents won't make the effort to learn the sign language.

**RESEARCHER:** How do you see services for people with communication disorders developing in Nigeria?

**FUNKE:** I would like to have something that is within the community, accessible to people. I wouldn't like to think that we are centralizing where people have to travel a long distance to get in touch. I would like things like community services and where it can be completed in the community there could be mobile services. .... I have to put to Ilorin to Kwara State...hearing tests and things like that.

**RESEARCHER:** Where do you do those? Where?



**FUNKE:** At Ilorin in the health Centre. There's a clinic in Surelere, I don't know if you know it? Where we do the hearing tests. So you find out that some people who need the services cannot even afford the transport fare.

**RESEARCHER:** So how do you think that can be organized? How can that sort of community service be organized, because you are working privately here?

**FUNKE:** I have sort of found out that things attached to the government here in Nigeria don't usually work very well. They may work in the future, but for now it doesn't. It starts very well and you think its going to...

**RESEARCHER:** Why is that do you think?

**FUNKE:** Well I think some of these services need dedication. You need people. Its not only having the material need that matters. You need people who can stand behind it and make sure that it works. Usually we don't have such people, or the people in the government who employ people to do certain things don't really get people who are dedicated to the programme and eventually you find out that the programme dies off. So I think we need someone who could be.....

**RESEARCHER:** Who could be?

**FUNKE:** who could be ..... who could be held responsible for making sure. I mean who would be responsible.

**RESEARCHER:** But this is a private person..?

**FUNKE:** Not necessarily a government person, because as you know the government is changing every day! Even when you have somebody who decides to do the thing he can be easily transferred to another programme and so forth and so forth. And so you find out that the thing dies down. So I have been thinking it may be better to have some private things done rather than a big government programme.

**RESEARCHER:** Is this happening in Nigeria? Because obviously its happening with you, perhaps in a small way. but you have started your own place and you've got groups going, parents involved and that's a kind of community approach to it. Are there other people like you?

**FUNKE:** There are some others who are ready to do such things. The stage we are in Nigeria now is a very difficult stage. Many people are interested in acquiring some wealth or some things. and when you have a programme that doesn't really bring much wealth many people don't want to carry out this service. But I still think there are some people who are ready to render such services. Even not counting the cause.

**RESEARCHER:** How would you see those people getting the training and information?

**FUNKE:** If the training is brought to the people it is sometimes better. We have to set up training for those people. If we find people who are really interested in getting training for those people then we have to get them trained where they are. I think they should be involved in the planning of the whole programme, we should get their own ideas. What exactly do you want to do? What service do you think you want to render? What is your own idea of the whole thing? And then we help them to develop the idea. Instead of having everything set and asking someone to come and... from overseas... which is what happens in the government programmes, everything is set and then they are just called,,, and aid will do the job. Then just to have DR. ALADE.

**RESEARCHER:** You're a Yoruba aren't you? Do you gave words in your language for disabled people?



**FUNKE:** Yes we do have. We call any disabled person 'ABIRUN'

**RESEARCHER:** What does that mean exactly?

**FUNKE:** Needing help in some kind of way.

**RESEARCHER:** What about deafness? Do you have some kind of word for that? word for that?

**FUNKE:** 'Aditi' or we have deaf and dumb, 'Odi'

**RESEARCHER:** Does that literally mean cannot hear?

**FUNKE:** Cannot hear cannot speak.

**RESEARCHER:** What about blind?

**FUNKE:** "Afoju" 'aju' is eye and When the eye is not open... 'Afoju'

**RESEARCHER:** What about Physically handicapped?

**FUNKE:** 'Aro' it means 'cannot walk'

**RESEARCHER:** Mentally handicapped?

**FUNKE:** Sometimes they called 'didiri' Somebody who cannot reason properly.

**RESEARCHER:** Do they have a word for people who cannot talk, specifically for people who cannot talk?... or any other words for people with disabilities?

**FUNKE:** I cannot think of any....

**RESEARCHER:** What are Yoruba's beliefs about people with disabilities?

**FUNKE:** The Yorubas and some of the Eastern people have a belief that's...er.. In fact the Yorubas have a word that's 'anebu' this means disgraceful, a bad mark for your family, sort of... and they don't want it.

**RESEARCHER:** Do they feel they are to blame? Is that the whole family or just the mother?

**FUNKE:** The whole family, sometimes the mother takes a larger share of the blame, you find, a couple comes in and they talk about their deaf child. You ask if there is a member of the family whose deaf, you say no and then he often says... maybe its my wife..I don't know where she got the child from! Maybe somebody in her family, but they never want to accept that its their own family.

**RESEARCHER:** So what might they do when they have a child with a disability? What is the procedure traditionally?

**FUNKE:** Traditionally they try to get rid of the child, it still happens. Somebody in the village, the child had a baby that had a problem, its already been growing. They took the child to the grandparents for them to take care, they just put this child in a room and starved her to death! I think he was mentally retarded.

**RESEARCHER:** Are some handicaps worse than others. Would it be worse to be mentally handicapped than deaf?

**FUNKE:** If a child is deaf and can move around that is not as bad as if he is physically disabled and also mentally retarded. The worst type of handicap is the one that affects



communication, traditionally society holds verbal ability in very high stead. You need to be able to communicate to have social standing.

**RESEARCHER:** Do you see the cultural structure of your country affecting the way the disabled are treated?

**FUNKE:** For example within the village structure in the rural area, if somebody is handicapped everybody runs round to see that the person gets the help they need. This is traditional, if the handicap is very severe you would probably want the child to die anyway, but if the handicap is slight they would rally round and help. for example I know some deaf people, and their family rally round to see that they get the help that they need to run the farm. In old Yoruba culture everybody in the same age group would help others in their own age group. Culturally they want everybody to have. You would not be left out of your own age group.

**RESEARCHER:** How much does it help for people to come to school when they have a handicap, if they can function within their own community is school helpful or appropriate?

**FUNKE:** But you know Nigeria has changed these days, most people want to live in urban areas, and because of that a lot of these structures we Are talking about have been destroyed, the kind of support that people used to have in their families... well we don't have that kind of support any more, for example in the past if I went to have a baby now, for three months I would not have to do anything, people would come round and help me! Now I have to do everything by myself. They all have their own jobs and are too busy!!!! So development is sometimes backwards!!

**RESEARCHER:** So would people in the past have had a better deal than they do now?

**FUNKE:** Yes I think they did because they were supported by their communities. In the past no family would have wanted to find one of their own members begging in the street, now you see many begging in the street. Family pride used to control this better They were given money taken to traditional doctors.

**RESEARCHER:** If somebody has a handicapped child now, is that what they do? Take them to the traditional doctor?

**FUNKE:** Yes, or spiritual doctor.. herbalists.. the example I have.. one of the children in our school... it was very sad. He did not come to school and they sent messages that he wasn't well, anyway they didn't bring him back for us to see. Anyway by the time he came back he was very sad and lethargic and eventually died.

**RESEARCHER:** What do most people do with their disabled children?

**FUNKE:** Nothing ! And that's what we have to work together with them to change! The ones who want help are always looking for something big and grand.



## APPENDIX 11b

## INTERVIEW WITH DR. MBA 31st. JANUARY 1994.

This interview was carried out with the assistance of Dr. Alade who signed interpretations when necessary and translated from sign for Dr. Mba when explanations were needed. Dr. Alade is presently a lecturer at Ibadan University, Special Education Department, in Deaf Studies. She has a hearing impairment and uses a mixture of sign and speech to communicate. The transcript below is taken from the tape recording made at the time. This recording was hindered by a very noisy cockerel and speech production affected by hearing impairment. It was helped by additional supportive signing and notes taken at the time. Some of the sections have been omitted as they were unclear, this is indicated by dotted lines. Other sections are summarized using information obtained from the signing, this is indicated by information supplied in brackets.

**RESEARCHER** Dr. Mba, could you tell us a little bit about yourself and how you came to be involved with educating the deaf and with special education?

**DR. MBA** When I was in my twenties I became very ill, and the drugs I was given to cure my illness were very toxic. When I recovered from the illness I couldn't hear anything. It was a big shock. I took a long time to recover. To get used to not hearing.....Then I discovered people who couldn't hear could achieve a lot and that I was needed. Later I went to Galludet in America and then came back to Nigeria to fight for the development of special education. I established the Department of Special Education at Ibadan University and retired from being the Head of the Department the year before last. I still go there I still have my office there. (Summary from speech and signing)

**RESEARCHER** How do you see the services for people with communication disabilities developing in Nigeria?

**DR. MBA** Are you thinking of Deaf children in particular or any specific area? Children with Mental retardation will have difficulty communicating too.

**RESEARCHER** That's right. We are looking at children who have difficulty communicating. So deaf are part of them, but also mentally retarded children and cerebral palsied children. So we are looking at it from the centre of the child who doesn't communicate for various reasons, the deaf would be one part.

**DR. MBA.** One part. The children wouldn't be able to express themselves in any way you may have to suggest some way and then see how, where, they follow the way you suggested. (Dr. Mba seemed to be indicating that the children and families should be consulted and then supported in their choice)

**RESEARCHER** Yes what's more .....tied to their own ideas?.....Your own knowledge. I think that it will be as much for us to learn as for them to learn?

**DR. MBA** Yes.

**RESEARCHER** Because it is new. In Nigeria it would be very new to approach the problem like that.

**DR. MBA** Yes.

**DR. ALADE** One way would be to suggest. For my masters I did a psychology, usually we worked with different groups-design a program. One way we do that is to include all professionals - we had a psychologist, we have counsellor - the child, the teacher, the parents, everybody would come together - try to find the areas of need and then focus on the areas and develop the kind of services the child needs.



**RESEARCHER** That's a very new idea. Does it happen here? Its exactly the philosophy we have.

**DR. ALADE** .....So that they put everything in the program/timetable for the child. A place where families can find out everything. Physiotherapy - time for class then the parents supply the necessary information about the child and then the psychologist can visit the home and observe the child at home, observe the home environment, see what is happening most of the ..... see if the parents are giving the correct information especially if the information doesn't show them up. They can learn to do it themselves. (explanation from signing with Dr. Mba)

**RESEARCHER** That is child centred and it has a very high professional input and so it is very expensive. Is this what students are taught at the University?

**DR. ALADE** Yes, but its very expensive and not easy for them to do when they leave.

**RESEARCHER** So we are looking at doing something cheaper

**DR. MBA** I think one other way is to ....organize help from a centre where people know they can go for help.....when you bring the children together you bring in a variety of play activities. This needs more time in the training of people who help.

**RESEARCHER** Yes.

**DR. MBA** Then watch them indicate how they could be handled and then leave for the children. You will find that some of them will be ?ataxic. Find activities that interest them. Find activities that sustain the interest of the children longer Notice these activities so that in future programs you can try to adapt move from that activity to something.... without..... gradually move from that activity from something better

**RESEARCHER** Does Dr. Mba think that the family could do this? Would it **have** to be a professional?

**DR. MBA** Some of the families do not have the interest, but sometimes of the families are very interesting. I think that the families should be involved. To learn what the children are capable of doing.

**RESEARCHER** How many families are interested and how many are not interested?

**DR. MBA** You may have to choose from literate families.

**RESEARCHER** You think that they are interested?

**DR. ALADE** .....

.....  
You have to decide from how many literate families you have.

**RESEARCHER** You are saying that it is a matter of general education?

**DR. ALADE** .....

.....

.....  
I decided that the best way was to get someone from the group to follow up whatever we did.....

.....

so that made it very difficult. Come back again, again and again. (Not clear from the recording obscured by the cockere!!)

**RESEARCHER** It is good for small numbers but it is no good for a lot of people so we have to think of something to help the other people that is what we are involved with.



**DR. ALADE** Equipment and materials

**RESEARCHER** That is no good if there isn't enough money.

**DR. ALADE** One to another words and phrases. (translated for Dr. Mba)

**RESEARCHER** What do you think are the priority for services. If you were planning the services for Nigeria, what would you do? How do you see services for people with communication disabilities developing in Nigeria?

.....

..... (Recording unclear, notes taken indicate that signing covered a lengthy repetition of Dr. MBA's priority for intervention with pre-school children involving the family in order to change attitudes and to educate them to realize what could be achieved for their children.)

**DR. MBA** I would start with pre-school education and the family.

**RESEARCHER** That would help with the education and understanding. Are student s trained to do this?

**DR. MBA** Yes but not enough practice.....Bring in play equipment and carry on to primary school level.

**RESEARCHER** I'm interested to know what you would do if you were the government. What would be your priority?

**DR. MBA** First you would have to start with one class. Two attendance to help. The children have to be able-bodied children who would start with activities, keep control, more activities, ordinary games.

**RESEARCHER** Which type of disability do you think is worst. most difficult for the person, the family and the community to deal with?

**DR. MBA** That depends. Depends of the person and where they live. Some get lots of help. Then they are better. Others have lots of difficulties. It is the attitudes that make the difference.

**RESEARCHER** How would you try and change peoples attitudes in the family?

**DR. MBA** I tell you what I would do..... Lets go outside I would show people what the children could do..... I would use the radio to tell people about it all. Direct activity and involvement.....Changing attitudes is most important. People think disabled cannot do anything good. This needs to be changed, but it will take a long time.

**RESEARCHER** What about making a video of what you do and then let lots of people see it? What you are describing is good but how can it be made to reach a lot more people?

**DR. ALADE** Its a good idea we have programmes on the TV. showing different ways of communicating. Its not enough to educate people in schools they do not attend long enough. If you come to our place for some weeks you can learn sign language.... you don't have to be deaf..... way of communicating. so rather she accepted that there was nothing wrong.....the students in my department.....sign language.....grammar because of that we have students in deaf units.....Nothing wrong with them accept that they cannot hear Boarding School, radio.....TV. (This represents the recorded element of a conversation between Dr. Alade and Dr.. Mba which was supported by signing.)

**DR. MBA** One other way of changing attitudes towards handicapped children is to play with them, develop special activities, invite people to come and see the activities....This could be transferred.....



**RESEARCHER** I think that helps to change the attitude

**DR. MBA** Yes change the attitude Take them out on a nature walk... as you go they encounter something very lively..... something like that.

**RESEARCHER** Another thing that we are looking at is that deaf people are able to communicate through sign but other people like mentally handicapped or cerebral palsy who are poor at communicating - They can't express their needs as well as the deaf so we wondered whether the deaf could be used to speak for other people who have trouble communicating. Now I wonder what you think about that? Do you think that they could represent the other groups?

**DR. ALADE** Problems communicating.  
They can always see what you do.....  
They learn by example.

**RESEARCHER** But if their mental capacity is not so good or.....they can't do.

**DR. MBA** It depends on.....  
But those..... the deaf..... it is important that they learn to sign then they can communicate..... others.....to sign ..... to talk together.

**RESEARCHER** So then comes the question should you send mentally retarded children to school? Do you think you should or not?

**DR. ALADE** They should be educated. (?)

**RESEARCHER** How do you know? If they go to school they spend a lot of energy going to school they may never read but they try - maybe that energy would be better spent learning how to speak or going to the toilet or learning how to dress better?

**DR. ALADE** These things are important.

**RESEARCHER** Maybe money is being misspent on educating mentally retarded children to read and write?

**DR. MBA** Getting their interest is what they like.

**RESEARCHER** But going back will the deaf being able to speak for the needs of those other people or not?

**DR. ALADE** .....  
..... O.K. I have been deaf for long  
So I put the deaf one in charge of the mentally handicapped one, she was the one who took care. She knew when he was hungry. She knew everything..... etc..

**RESEARCHER** So you feel there is an advantage in putting the different disabilities together, one compensates for the other

**DR. ALADE** Yes, the deaf work in the tool shed....the others help. ....the deaf feel needed.  
.....the Physically handicapped speak for the deaf.

**RESEARCHER** This is very good for self confidence, to help somebody.

**DR. ALADE** Yes and their independence. I have another mentally retarded boy.....that one seems kind of responsible. The job that makes him feel good and even the parents commented on his development. The boy has developed confidence. He pushes the wheel chair for the others.



**RESEARCHER** This is not an expensive intervention, it requires very little money.

**DR. ALADE** That's right.. just putting them together so they can learn to be more helpful.

**RESEARCHER** So you feel that would be a very good thing to promote because it is cost effective?

**DR. ALADE** Right. A very good thing to promote.

**RESEARCHER** So what you are suggesting here is pre-school help and putting disabled people together to help each other

**DR. ALADE.** Yes.

**RESEARCHER** Those are good ideas and they are not costing any money.

**DR. MBA** Good idea. When you are working with these children you have also to provide, appart from learning, some activities. Re-enforcement..... directly.....what you want.....re-enforcement.....praise.....oh yes.....oh.

**RESEARCHER** Well its been very nice to talk to you.

**DR. MBA** one thing I want to emphasize.....the activities you plan should include physical activities.

**RESEARCHER** But it should be drama from Nigeria not drama from Western countries?

**DR. MBA.** Yes also something.....do it well.....lead to another thing.....they need to do it well.....next time they know what to do.....and from that stage you lead them on to another and they know what to do.....reading and writing come last.

**RESEARCHER** After they have communication and self confidence? What about language difficulties?

**DR. MBA** Yes If children.....learn to use sign language.....they prefer sign language to finger spelling.....for them to learn the required.....what is your name? ....My Name is John.

Your book is very interesting....they are always borrowing it.  
.....



**APPENDIX 11c.****INTERVIEW WITH PRINCE PAUL IN JANUARY 1994.**

Some sections of this interview have been summarized, but other sections are transcribed in full. When the wording is unclear the omissions are represented by dotted lines.

(The interview began with a discussion about what I would be doing in Uganda when I moved there later that month. Prince Paul described his involvement with the International Disability Movement and his associations with disabled people in Uganda and elsewhere. He congratulated me for my involvement with disabled people and my contribution towards helping people turn from begging to trading. We discussed the merits of CBR News and how it could be helpful to people here in Nigeria. Prince Paul felt it could provide an opportunity for people in Nigeria to communicate with other disabled people in other countries. He continually emphasized the importance of involving people at the highest level in planning services for disabled people.)

**RESEARCHER** Can you tell be a bit about yourself and how you came to be involved in providing services for people who are disabled?

**PRINCE PAUL** I was born with this disability, without proper arms and hands and the local school rejected me .It was difficult for my parents. They found it difficult to accept me. They did not know what to do. The hospital offered to do an operation on my hand but my parents refused, they were frightened. The Hospital was a mission hospital and they made my parents sign an oath that they wouldn't kill me. If they hadn't done that I would probably have been killed. Eventually I was accepted at school because I taught himself to write . I was always top of the class, however when it came to secondary school I was rejected again, however we went to the Oba of Ilawo and eventually got in. When he left school I got a job with the Government in the Treasury Department and eventually got a diploma in local Government Administration from the University of Ile Ife. When I went back to my government job I was often asked to talk about disabled people. In 1990 the commissioner of Oyo State asked me if I would be prepared to take over the running of the Rehabilitation Centre at Moniya , it was very neglected at that time, with only a few 'lunatics' being kept there.

I worked hard to make it a participatory project, the buildings have been constructed by the Federal Government, the State has contributed as well as Philanthropists, the staff are paid by the government and 10 of the staff are disabled themselves. They have 60 trainees with many different disabilities, they stay one year and then go home and start their own business. They are starting a new programme to help support families when the disabled person returns home as this is a difficult time for them and their families.

**RESEARCHER** How do you see services for people who are disabled developing in Nigeria as a whole?

**PRINCE PAUL** We need to look after them, give them training and education in schools and institutions. These need to be well run. They deserve that. These children are just thrown out of the house.... we need to open their eyes, explain things.....when a child is born today we must explain things so that they understand and will not throw them out. They need to be looked after, you need matrons responsible women and nursery education so that the children can learn.

**RESEARCHER** What about the families?

**PRINCE PAUL** The families would be involved. We are going to establish this place. They wont throw them, they won't neglect them. they wont just dump them with us.

**RESEARCHER** But maybe they just cant face the problems they bring for them?



**PRINCE PAUL** We will help them face the problems.

**RESEARCHER** Some people feel that if you produce institutions you really allow and encourage families to relinquish their responsibilities. If the child goes into an institution, maybe the parents pretend to be interested for a while, but after a year or two they go. The child is left with no family. When they have finished, (you cant have them in an institution all their lives) they have nowhere to go. How do you feel about this?

**PRINCE PAUL** It is one of the problems. Yes they drop them there and they don't come back again. That way you have to be careful about how you take in disabled people.....must be adjusted to.....someone from the world.....one of the relatives must also attend.....be able to treat through these people.....3 terms a year. pick them through the parents so the parents can be involved...parents must visit...there are social workers whose job it is to treat the family .....counselling.

**RESEARCHER** It is an expensive way of dealing with the problem when you think about the numbers of people who need help. Around 6% of the population? Its a lot of people, a lot of Institutions!

**PRINCE PAUL** You know when you are talking about this percentage.... not all the people will want the same sort of help.....some of these numbers are part of society. ....some will go to local schools as I did.

(the discussion continued concerning the provision for disabled people in nursery schools and normal schools and whether they would take children who were disabled.... there seemed to be no conclusion on whether this was possible or desirable.... Prince Paul then outlined how he obtained funding from people who he persuaded had an obligation to provide for disabled people from the revenue of their businesses. He felt every one should give something, a sort of disability tax of around 1%)

**RESEARCHER** Perhaps getting the money is not as difficult as knowing what to do with it.?

**PRINCE PAUL** I have been able to do certain things because of my experience. I have told you once the way I was born. I never thought there would be schools specially for the disabled. I went to normal schools. That gave me the opportunity to compete very well with able-bodied. In my school days I discovered. I always said to myself, I must talk to someone.... not beg.....but because my parents felt.....struggling among abled. I was ahead in the classroom work even football. Don't do it, you will wound yourself. I said no, let me try I will do it. I have small farm. I do the small farm myself. I discovered that if you give the disabled person the resources.....

**RESEARCHER** Do you think that amongst the different disabilities some are harder to handle than others? Or do you think that's just the way we observe it?

**PRINCE PAUL** Those who are very hard to handle are the mentally retarded.....has certain potentials.....they need to deserve their potentials.....but.....he wont do it. But he can do things.....methods .....practice. Just give him things to do.. that..because they have seen you doing it they will just do it. They learn by example. They are difficult because people want them to do things. They have to be taught everything.

(the discussion continued considering how Nigerians coped with disabled people. P.P. gave the example of blind people having a difficult time)

**RESEARCHER** Does it make a difference traditionally about passing down property or responsibility, or status in the community. You are from an important family. If you had been deaf would you have been able to maintain your position in society?

**PRINCE PAUL** There are many differences. I may not be able to do as I am doing now.



If you have intelligence...Physically handicapped is even better than being deaf for instance. People do not understand and are frightened like my parents. They may think there are good or bad spirits in disabled but which ever way they will be isolated.

**RESEARCHER** I am wondering if the key to it is being able to communicate?

**PRINCE PAUL** The deaf have problems communicating, in fact their only problem is communication. Many disabled cannot communicate well.

**RESEARCHER** But the deaf do communicate remember through sign language. OK, its not to everybody, but they can communicate. The person who is mentally retarded has difficulty communicating.

**PRINCE PAUL** The deaf have an advantage, if there are 50 together.... they are talking.... no one knows what they are saying... if we observe.. who is deaf? this is deaf culture.

(A discussion followed on the different disabilities and their effect on the family. P.P felt it was harder to have a child with cerebral palsy than a straight physical deformity like himself.)

**RESEARCHER** If you are disabled is it better to live in the city or the village?

**PRINCE PAUL** Better in the city. In the village nobody will give you priority or money, here in the city people will give you money and attention.

**RESEARCHER** Do you need money in the village?

**PRINCE PAUL** We don't need money in the village. My concern was just to eat. Give me food. I am satisfied.... dressed at ceremonials.....dressed at ceremonials...but here in Ibadan..... drink... sweets... many things are going on. When it is a matter of food you sit down to eat, the disabled included.

**RESEARCHER** In the town you have to have money to eat.

**PRINCE PAUL** That's important.

**RESEARCHER** You might be able to get enough money to even eat. So what I am saying is that you might be better off in the village.

**PRINCE PAUL** Perhaps.

**RESEARCHER** Do you think it would be possible to introduce some kind of achievement or way in which the disabled could achieve in rural areas?

**PRINCE PAUL** Yes that is why we are promoting community development work. the most important thing is for them to learn to look after themselves.

**RESEARCHER** Would that be preferable to going to the city?

**PRINCE PAUL** The city is better, at least you will have reason in your life. Life is better for the disabled... employment support, clothes food....

(the discussion continued but no amount of persuasion would change the prince's mind that the city was better for disabled people, even though he agreed that there were not enough places to help disabled people in the city and many people received no help he obviously felt strongly that the village was 'very dull and lacking opportunity')

**RESEARCHER** So given the limited resources because there is always going to be very small amounts of money available for developing services for disabled people. What do you think is the most important thing to do? What is the priority?



**PRINCE PAUL** What is important to do is to identify trades where people can be trained, once we get that, the carpenter, shoe maker. We have to give each community the chance to decide. Put them together we can attach them to a trader.

(PP. was asked if in Yoruba culture there was traditionally someone who was allocated the job of 'looking after' disabled people in the villages, the Prince had not heard of this before. He said traditionally if you were disabled the spirit of God was with you. The disability was attributed to an evil spirit, someone had done wrong and wanted punishment, but the disabled person may have a spirit which is powerfully good. People call on disabled people to help them communicate with God. Nowadays people don't really believe this as they are interested and aware of the causes of disability. The interview ended with a description of PP.'s latest money raising project for his Institution and how he planned to spend it. He was congratulated on his ability to do this and on all the services he had managed to establish for disabled people in the area.)

APPENDIX 12. TRANSCRIPTIONS OF FOCUS GROUP DISCUSSIONS.

MOTHERS FROM MARIA’S CHURCH.

(Some parts of this recording were difficult to decipher, the absence of data is recorded with .....)

R: Do you know people personally who are disabled? Do you know people who cannot hear? Have you ever met people who cannot hear? Have you ever had anybody in your family with those kind of problems?

All: No.

R: What about blind people?

All: No, not in our families.

R: What about people who find it difficult to learn? To understand?

M: .... saying well. There are people on the road like that, we do not live together with them.

R: When you see them on the road, what do you feel about them? Do you talk to them?

M: If you see them on the road you cant go near him or her, you don’t know that how the thing is worry them. What they will do. That is why you cant go near him or her. You can try to remove yourself.....

R: Yes some of them look very strange, I agree. But then some are harmless.

M: Some is quiet. Just look and pass.

R: Would you say hello to them?

M: No we cant greet them, we would pass.

R: Why wouldn’t you greet them?

M: Because they cannot answer you.

R: When you greet people do they always answer you?

M: Yes always! because if you greet him or her, he can quarrel with you, because his head is not right.....  
.....for himself.....

R: What about people who are physically disabled, people who have a bad leg/arm. What do you think about them? Would you talk to them?

All Yes.

R: You would talk to them?

W1. If you get something you can give to them.

R: And then the deaf?

M: Yes you can talk to the deaf. You can move you can say something.



R: Are you familiar with people who have Cerebral palsy? They cannot move their arms properly and they tend to make funny movements with their legs and arms? Do you know those kind of people?

M: Not sure.

R: They can't walk because they can't control their body. Have you come across people like that?

W1. We have seen them for us.

R: Would you talk to them?

All: Yes Yes.

R: So its really just people who "are ill in the head" that you would not stop and talk to?

All Yes that is all.

R: But non of you have people like this in your families?

W3. No not at all

M: No.

R: So non of your brothers and sisters have any babies who have these problems?

All: No.

R: What about people who have a cleft palate? They have a hole here and a hole in the mouth. Have you seen them?

M: When I was little I saw him. I saw the man near our village. We went to see him, we met him on the road. So when I came back I asked my father, what make that man be like that? The teeth come out and the lip is cut. He told me a story about that.

R: Tell me the story.

M: He said that.. so there is one culture please which they have on the outside.. it is called Egungu. During that time when they saw... in our culture... women can see, when you see you run and hide in the bush and it is big and black. During that time.... if it comes out on the road you can run....

R: Is this a kind of spirit?

M: No... You cook food, you know the food when you take it up from the fire.. the food is very hot.. we carry that food, go reach that place where they beat the drums. They take it up from the fire just in the pot. So the thing was still hot, just like that.. because they eat first thing, they do not eat it again. so the man had to carry that food, just leave it on the fire, so the heat of that food enter the brain and from that the problem arose and he cannot talk.

R: Did you know that they can have an operation to close the hole?

M: No can they?

R: My goodness these are the twins, I remember them when they were very small, Elizabeth took some photos of them.....

W1: To another one at my father's house, so from there he do bad things... If he do them

maybe he come back. The evil spirit enter the belly and he will come back you know. If he does die he will come back again.

R: Do you think that this is true?

W2. Well my father told me!

R: Well it is probably true then. But is it the fault of the person or their parents?

W1. Yes.

W2: Maybe they do bad or Mother or father.. so after.

R: But is there a difference between somebody doing something bad and then being punished, and them doing something bad and their child being punished. If you did something bad wouldn't you hate someone to come along and punish your child?

M: Yes yes.

R: Do you make a difference between the way you treat a person, whether you think its their fault or if you think its the parents fault?

M: Not the same.... if you do something bad, the person cant forget it, he can still remember that is.....

.....from that type of sickness.....

R: So when somebody has one of these problems do you feel you can do anything or do you feel it was god's will. Do you have to accept?

All: We don't want to do anything.... we just leave it to God.

R: So when people like me come along, a European, and say 'help this person' do you think that's OK?

All: Yes.

R: Its all right for us to come and help?

All: Yes.

R: But you don't want to help them?!

(Laughter)

OK. So its all right if we come and help, you don't mind that... but YOU don't want to interfere?

M. No not at all!

R So if one of your babies what would you do? Lets say one of your babies was deaf, he could not hear, what would you do?

W1. If one of my babies died...

M. No, deaf!

W2. I will go and find out... my family will help me..... I will take to the hospital to the doctor, to the healer to find out..... We would pray and pray and pray.



R. So if the answer is that your child is deaf what will you do?

W2. I will pray to God that it is OK.

R. If one of your twins were deaf and one OK would you treat them differently?

W2. No.

R Would you?

W1. No.

R. So you will talk to the one who hears and you will also talk to the one who doesn't hear?

W2. I would talk to them both.

R. Even though one does not hear?

W2. We talk with our hands.

R. So what if one child is ill in the head. He is mentally handicapped, so he finds it difficult to learn to walk, difficult to learn to talk, difficult to learn to carry water properly and do jobs for you... And to remember things?

W2. I would pray for him.

R. Would you take him to hospital or a clinic?

W2. Yes.

R. Would you take him to school.

W2. I would take him.

W1. Yes I would take him, because there are ones for children like that.

R. Yes there are special schools. So you would take him to a school. What would you hope he would do when he grows into a big man?

M. He wouldn't do anything.

R. Why not?

M. Because .....that school.....people cannot do anything.....before he.

R. So lets say one of your twins had a bad leg. What would you do?

W3. I would take him to hospital for medicine.

R. You would take him to the hospital and hope that they would cure him? What happens if they cannot cure him?

W3. They would cure.

R. But they might not be able to, God might have made him like that. What would you do, then?

W2. I would carry to the hospital get treatment.

W1 He would be OK.

R. Would it make a difference if you W1, are her friend.. if one of the children were handicapped? Would you talk to her differently? Would you react to the children differently?

W2. No.

R. But you began by telling me that when you saw people that were handicapped you left them alone.

M. Some of them, only some of them.

R. Ah so if it was your friend's children it would be different?

M. Yes. ....if you get money in your pocket you can take it and give it to him or her. You know many of them are taken off the road.

R. Yes I know. Do you give money to beggars yourselves?

M. All. Yes.

R. Even when you think they could go and work somewhere?

All. No.

M. Yes you.....it too late.....I cant give that one.....

R. Now you all live in town. I know Maria doesn't come from here. Do you come from here?

W1. No... Ikara

W2. Yes Ibadan.

W3. No Bendal.

R. You are a long way from home. So why did you come here?

M. The reason I came here was it work for you madam! You know it is good for someone to travel than to stay in your home town. You travel you get better.

All. Yes Yes.

R. But you can travel and still go home.

M. Yes... we stay here and later on we go back.

R. I see, you always go back?

All. Yes Yes.

R. If you have a handicapped person as part of your family if that person better to come to the town or stay at home?

M. What would he want to come here to town?

R. So you think he is better at home? He might come to town to go to hospital.

M. Yes, yes.



R. He might come to the town to beg of money.

M. He cannot come for that.

R. Well he does.

All. Ha Ha.....

R. If a child is handicapped is it better for them to be here with you or to be with granny?

M. Better to come with you.

R So then he would come here?

M. Yes he would stay with you... you cant leave your pickin back.

R but do many people do that? Do many people leave their children with the family/home village? Or does everybody stay together with their children?

W1. Some people do.

M. Sometimes parents at home.....they are not going to school. You cant take him from their home so you would leave them. After they have finished school, if they can get something to do. they can stay here. He can come visit you at home. He will come back to see you. No he cant stay forever.....he can go fine back. You can leave your pickin at home, go and stay for Ibadan. If everything OK. you call him. It is because of school that it why you.....

R. Is there not schools where you live?

M. Yes there is school.

R. So why come here for school?

M. The reason they are coming here for school is because I am here. We have lots of school all the local government in our area. But you cant stay alone you must have your pickin near you. Too much learning all the time.... too much alone.... you will see whether you are well or not.

R. You also have your children?

W1-W2 . M. Yes.

R . What about people who hide their children who are handicapped?

People who keep their handicapped people inside, so that people cannot see them?  
That happens?

All. MMMMMM..... Yes.

R. Because they feel hurt and sad about having handicapped children? Is that right or?  
What do you think?

M. What do you think? W1/ 2/3. ....pause. That's why I called them here.....pause.

R. I think that people do that- am I right?

M. Yes.

R. Because they feel sad or guilty or ashamed?

M. Let me come... speak. One this is.  
Even though you have a pickin... and he cannot do it... things. Its not your fault.

R. Its not your fault?

M. Yes because the .....is in the words..... you don't know what is inside when it comes out. You continue to training him— you keep on trying. You cant do anything to him because he cannot do things. Can't do bad things for him you continue to feed him. You continue to train him, you will keep that type of child. You don't know tomorrow, there is nothing but to thank God. If you pray maybe by the grace of God. If you two eyes close, and pray hard maybe he can help you because of your sad. You cry he sees- cry every day to God. If you continue to cry and pray maybe God an help you. He can do everything. There is nothing that God can't do.

R. God can do everything.. If you have a handicapped pickin in your family what can YOU do? Lets leave God for a moment.

M. There is nothing we can do, we can take it to the hospital if you take it to the hospital...

R. You can feed them?

M. Yes. well well.

R. You can talk to them?

All. Yes.

R. You can help them to learn.

M. Well well, you cannot leave him alone- everything.

R. I think I have asked you everything. Which do you think is worst?  
Which one would you hate to have yourself?

M. Crazy.

R. the crazy people are not always happy because they don't know whats happening..... maybe they are quite happy those crazy people? People who are blind/deaf, because they know what's going on and they cannot do things. Maybe they suffer more, perhaps the crazy people suffer? Hardest for you to handle is that what you mean?

M. Yes hardest for us.

R. So if you were the President of Nigeria.

M. Ha Ha let us laugh!

R.... and you had to decide how you were doing to help handicapped people, what would you decide to do? Would you decide that they need help or would you just leave it?

M. Help them.

R. So how would you help them?

W2. I would have to help my family and if work for you... work for country... come and meet them, take care of them.



R. What would the President do? How would he organize that? It might be difficult.

W2.....

R. And we haven't had your contribution (W5)?

M. (Translates.)

W5. I call them... I would make one big house. I would make one big house and give them everything they want.

R. Oh! They would become monsters.... Ha.....?

But what about if they wanted their Mummy or Daddy brother and sister.....?

You say you would give the child, the handicapped child anything they want...? Perhaps he wants his Mummy?! Laughter.

If you put them in a big house altogether they all want their Mummies maybe? Its not easy to know what to do?

M. Let me try small.

R. Yes President Maria?!

M. The thing to do. Oyo State. If those type of people stay in the State. I can do one place for them.

R. Like your friend you build a big place?

M. Build one like marvelous. If these type of people stay like that. I can do some projects for them build a place. Some of them are small they cannot leave their parents, they are small to go stay there away. The only thing I should do. I would make sure the people who look after that house keep the place clean, and food for plenty. Come and register if and come and see the children with money to go and keep them. Then the children belong to the government. They not belong to you again...

R. Where will the Government get the money from? They get them from Maria?

M. The Government can use money or people who need. They can open school for deaf.....that one class deaf one class..... those for sort of sickness.... we can give them now. Give them on... one room.

R. But this will cost a lot of money.

M. I know I know... It will a lot of money, but it will stop them roaming about the country.

R. But when they finish school what will they do?

M. When they have finished school. Many.....SO.....

If I get money I can open my open my own company. some if for the Government.

It is for the Government alone.... if he know how to write I can fix. Not all of them.... we could fix one here Ha ha!!

R. It needs a lot of money.

M. Those sort of people.....

some can be secretary so continue and talk.....

R. Many can write and many are very bright, very clever.

M. As you hear me say so... one place and give them food.....if not enough for me...not your fault you find your own way as myself.

R. Thank you very much for talking to me It nice to know what you think about it. I will leave you in peace now. Thank you.

## APPENDIX 13

### TIMETABLE FOR COLLECTING DATA IN EASTERN UGANDA.

- 2.12.94** Contacted Chief Rehabilitation Officer, Mr. Jackson Mirembe to make arrangements for data collection.
- 7.12.94** Travelled to Tororo, met with Senior Rehabilitation Officers conducting the training course for the Community Development Assistants (CDAs).
- 8.12.94** Conducted Training session in Tororo for the Mbale CDA's in the use of the questionnaire. Modifications were made to the questionnaire on the groups recommendations. 18 CDA's Gave out 20 copies of qu. to each CDA.
- 20.12.94** Travelled to Tororo.
- 21.12.94** Conducted training session for Tororo CDA's gave out 20 sets of questionnaires. Conducted training session for Iganga CDA's gave out 19 sets of questionnaires. 58 CDA's involved in collection of data. A list of the CDA's can be found in the appendices. 1220 qu. handed out initially. Plus a further 170 on later visits.
- 19.1.95** Visited Mbale to check progress and check for any problems. Met and discussed issues with some of the CDA's and the DRO. Visited two deaf children in their homes with Alex Mubajje.
- 20.1.95** Visited Tororo CRO to check for progress and problems  
Visited Iganga CRO to check progress and problems.
- 31.1.95** Travelled to Tororo.
- 1.2.95** Tororo Field visit to Masaba to visit Mr. Mugoto and Kwapa to visit Mr. Oguti.
- 2.2.95** Tororo Field visit to Kirewa to visit Mr. Oyango and Buteleja to visit Mr. Dakkar.  
Return to Kamapala.
- 7.2.95** Field trip to Buhugu and Buwalasi sub-county to follow up Mr. Khaukha and Mr. Nakedi.
- 8.2.95** Field trip to Bulucheke s/c to see Mr. Wamoto David  
to Bushika s/c to visit Mr. Mabala  
to Bakiende s/c to visit Mr. Wamakota
- 9.2.95** Field trip to Sisiyi Sub-county to visit Mr. Namawa.
- 10.2.95** Field trip to Magada s/c to visit Mr Mpiiya Stephen.  
Field trip to Ibunku s/c to visit Mr David Kaeteyi.  
Field trip to Iganga town to visit Mr. Ngobi Geoffrey.  
Return to Kampala.



## APPENDIX 14. FIELD NOTES FROM SURVEY 3 IN EASTERN UGANDA.

### MBALE FIELD NOTES.

The DRO was visited on 19.1.95 to check if there were any problems with administering the questionnaire. The meeting was held with the Community Development Officer CDO a Senior Rehabilitation officer from the Ministry and a number of CDAs. The following points were raised for clarification.

1. Clarification of the definition of a child. (0 - 18 years in keeping with the official Ugandan definition of a child.)
2. Can the answers to the questions be different for reported and observed? Yes.
3. Can the worker and the child come from a different area? Yes but its unlikely.
4. Expressed frustration that they cannot visit as many of the children as they would like due to transport difficulties. It was explained that it was not a competition to see who could visit the most cases, and they should only deal with the ones that they could manage, filling in the forms for everyone under 18 years of age. Regina explained that the bicycles would be forthcoming after the next training session.
5. Clarification was required again that the questionnaire should be given to ALL the cases that they saw under 18, and NOT just to the people with a communication disability.
6. Some Families had asked for an explanation for the questionnaire and so the explanation was repeated so that CDAs could confirm that they had understood clearly and would be able to communicate this information to the families. ie. the questionnaire is trying to gather information about the proportion of disabled children who have a communication disability regardless of the cause. It is felt that the proportion will be high and that there should be more facilities, materials training and research about how these children can be helped.
7. In addition to answering the queries:
  - a check was made on how many forms had been filled in so far.
  - and if there were enough copies of the questionnaire for their use.
  - It was agreed that the next visit to Mbale would be on 7th 8th 9th March.
  - The DRO and the CDO were informed which CDAs had been selected for the monitoring process.
  - It was agreed that the DRO and the CDO would make out an itinerary to visit the selected CDAs on the dates selected.
8. Before leaving Mbale a courtesy call was made to the District Executive Secretary DES. to inform her of our activities in her area.

Field notes 7.2.95.

Left Tororo after delivery of typewriter and duplicator. Met briefly with Mrs. Bwire.

Arrive Mbale 10am.

Programme they had arranged was now scheduled to start until 2pm. so took the opportunity to visit the Greenlands Rehabilitation Centre.

- Disabled Director
- supported by Action Aid.
- lot of infra-structure investment.



- wonder how sustainable it could be?
- Made tents and canvas items very costly, ? quality control and marketing?

Also visited EARS Centre, situated in Central Administrative office. Met Inspector of Schools and the EARS teacher, Josophine. Issues of note:

- Office had been refurbished by EARS, very smart indeed, made the rest of the offices look very shabby wondered if other staff were jealous? ? too smart?
- Just 'sensitizing' people at the moment.
- Felt they may be promising too much, wondered about the wisdom of assessing when no real facilities to help exist, would be better registering.
- Child centred approach.
- Teacher reported difficulties as.... - parents have high expectations.
  - process of assessment difficult.
  - onward referral to whom? for what?
- wondered if teachers can become assessors with such minimal training?

Left 1pm. to visit Khaukha Johnny and John Nadeki plus the DRO and the CRO  
 Khaukha had filled in 20 forms, seemed to understand they were for all cases had seen a number of adults in his area as well. He had obviously worked hard and was very proud of the progress some of his cases had made. (This was the man who had been attacked and stabbed in his own house when robbers had come to steal things from the small shop that he ran.

Visited Bisanzu Buhugu at Lubidio. This child had ?polio at one year old, this had paralysed his legs and possibly some paralysis of the speech musculature. Delayed speech development. Child's Mother had made parallel bars and his legs were getting stronger every day. No problem with eating which was surprising. A duplicate monitoring form was completed.

Visited Regina a deaf young women who had married and then been returned home. Bumaludi village. Discussed the alternatives for her.

Also in the same family Madoi 7 years old partially hearing, could follow if you shouted. Advised contact with EARS programme for assessment and possibly a hearing aid. Encouraged family to send him to the local school.

Also visited the CDAs own home and met his wife and 3 children.  
 Called at the RC's Offices to greet him, sign the visitors book and explain what we were doing in his area.

With Nedeki we visited Gadi Kadoli at Kyeuwumbungo. The history revealed that he had juvenile arthritis. Fever regularly with a lot of joint pain, could not bear to be touched. small child with legs like sticks, recommended the use of aspirin, plenty of rest when in pain, plenty of food when he feels hungry, (did not eat when he felt ill) It is good to take exercise when not in pain. Filled in the monitoring form, no indication of any kind of communication disability.

Also in the same village visited a Deaf girl Caroline Lusika aged 6 years Discussed the pros and cons of sending her to school. Sign language? Who can help locally?

## 8.2.95.

Visited Morini Nabutiti with Mr. Wamoto. Shiruku village Intellectual impairment, resulting in slow speech and language development. Advice and demonstration re language stimulation and play activities.



Agatta Bunemeya village VERY frightened of me!!! Screamed and if I came anywhere near her, or if I walked with her Mother or Father, she thought I was going to take them away.... would not shake hands with me. Excellent communication skills 4 years old, very small, had polio could not walk but the family had constructed bars to help her and she was improving daily. Talked about diet ,worms, exercise. Very poor but caring family.

Butiri village, up in the hills, local chief led the way, very steep, but he walked very quickly difficult to keep up with him. Wonderful view from the top. Man we talked to had 35 dependents four identified as disabled may have been more. Very very poor community. No good talking about making toys out of things you throw away, didn't have anything to throw away, no bottle or bottle tops, no tins or containers, houses needed repairs would not be water proof and they must get a lot of rain up there. It rained while we were there and we got quite wet when we walked down the hill again to the car.

Medina deaf girl 16. Had been to school P7 would benefit from trade training, CDA to look into sponsorship for her to learn tailoring.

Wangwa Bakari, cleft lip child, put on list to be considered when plastic surgeons come next time, no cleft palate, speech reported to be reasonably OK

Nandutu, small 4 year old deaf girl pretty dress!

Grace - eye problem

We were invited to "greet" Mr. Wamoto's family this meant a 5 course meal in his home!! He had lived there all his life, his father lived close by, he knew everyone in the area, his house was dark but smart and clean, his daughter had prepared the food, I think she had taken time off school to do it, his wife was out at work, she was a nurse in the local health centre. We had hard boiled eggs, chicken, liver, bananas, tea, coke, goat stew, potatoes. As usual a jug of water and a bowl for washing your hands was brought round before the meal which was eaten with your fingers. We were greeted by everybody who lived in the compound, but left to eat our food alone, I think they would have eaten later.... what was left. All the women greeted you by kneeling and shaking hands, the men just shook hands the African way. The women always sat on the edge of the circle never in a prominent position. It was difficult to get away without being rude, by the time we left there was a queue of disabled people wanting help and advice outside the door!

Mr. Wamukota took us to see Robert, we were passing his area and although he had not been selected, the DRO had arranged for us to call because we were so close. Robert was at home alone, he wore no clothes, he was mentally and intellectually impaired, he could not sit still, he could however understand and carry out simple instructions. Talked at length with Mr. Wamukota about behavioural issues that he could try and help the parents with, discussed the problems that they as parents would be presented with, coping with a child like this, and what a CDA might be able to do to help. Attitudes, discipline, safety, stimulation. Developing a needed life role in the community, if possible, as the eventual aim of any assistance.

9.2.95.

With Namawa Paul of Sisiyi s/c ( had met Heather Barber, VSO Speech Therapist, on matatu with forms! - very bright personable guy) visited Khaukha Aroni, selected at random for monitoring. Physically handicapped, polio, contractures. Talked about what assistance he could give the family. Speech understanding and hearing appeared normal.

Also visited Waniaza Budala. emotional behavioural intellectual impairment? More like mis-handled ESN. This child has improved tremendously since the family started to take notice of him, lives with his Grandparents, parents well off and live in Kampala, never come to see him. Talked a lot and people seemed to understand him, although his speech was reported not to be normal he could communicate well. Wants to go to the school, which was next door, encourages the family to take him. He may never be a star but he would benefit from the company and the stimulation. He could become very exited but was obviously delighted to be the centre of attention. Grandparents lovely with him.



## TORORO

The District Rehabilitation Officer DRO Tororo Mrs. Bwire, the CDO, the senior Rehabilitation Officer and myself met on 20.1.95 to discuss any problems that the Tororo District CDAs might be having with collecting the data about children with communication disabilities.

Before the discussion took place we met the District Executive Secretary, Mr. Okurut for a courtesy call to inform him of our presence in his district and to let him know what we were doing. Mr. Okurut was very interested in our work and made several interesting observations. He pointed out that “dumb” children were often “used” for smuggling purposes in this area as it was so close to Kenya. and “Dumb” children could not reply when asked awkward questions at the boarder and often got through unchallenged. Unfortunately this often meant that they were used by bad men. The disabled were also often “used” to look after the compound, the deaf or physically handicapped being left in charge while all the others went to school or work. He felt that the attitude towards this groups of people was not good, and efforts and education was needed to change it. Anything that we could offer to help with these issues in his area would be greatly appreciated.

The points raised in the discussion by the DRO and CDO were:

1. Confirmation was needed as to the age range required when filling in the forms. It was re-confirmed that it was 0 - 18 years.
2. Confirmation was also given that the forms should be completed for everybody the CDAs see, not just the children with communication disabilities.
3. There were reports of transport problems, but it was explained that although this was obviously a problem which needed to be addressed through the Ministry it did not make any difference to the data collection as the CDAs were only supposed to be filling in forms for cases that they were seeing in the normal run of their duty, and not going out looking for cases. It was explained that it was better to see a few people well, rather than see a lot of people but not really help any of them.
4. The DRO was asked to check the forms when they were returned to her to make sure that they had been filled correctly, before handing out more forms.
5. The DRO was informed of the names of the selected CDAs who would be visited for the monitoring process next month.
6. The dates for monitoring the Tororo CDAs were decided upon, 1st. 2nd. Feb. and the DRO was asked to draw up an itinerary to meet and monitor the selected CDAs.

1.2.95

Visited Mr. Mugoto of Masaba Disabled Group local NGO., Mr. Mugoto had filled in 18 forms filled in 3 more the day we visited him, there did not seem to be any confusion with him about who the forms should be used for. So 21 children seen by him so far, and he had filled a form for each one regardless of whether they had a communication disability or not. Case selected for monitoring was Florence Nekesa, congenitally deaf 16 years old. they think! No birth problems or serious illness to report. Went to school for two terms when 11, now stays at home and helps with all the chores. Mother says she is a good worker and seems to be an accepted and important part of their family life. I did not get the impression that she was rejected or used as cheap labour. Communicates with signs that the family have evolved themselves. The family is proud of her because she does her work and greets and entertains people so sell. Keeps herself clean, like pretty clothes. Talked about increasing the number of signs she used, family said would be very interested if someone could come and teach them all more signs to use with her. Discussed



this with the CDA. Possibility of trade training also discussed, and also the possibility of her being used as recourse person for other deaf children in the area. Mr. Mugoto had gathered all his cases under a wonderful tree in the middle of the village, I hope the photos come out, all the children he gathered were seen by someone from the visiting team, After completing the monitoring process I saw a Child who stammered, a 6 year old deaf girl, partially hearing boy with Otitis Media. and ?autistic child with behaviour problems. appropriate action was discussed with the parents, and community workers in each case.

Mr. Oguti in Butaleja s/c at Kwapa had seen about 100 cases altogether only 12 of these were children and he had filled in a form for each of them. He had no problems with the forms. We saw a few under a tree first, and then after selection of the case to be monitored, went on to this compound where there were a number of disabled children, we were greeted by a blind drummer who attended a school for the blind and was doing well there. He drummed on a plastic gerry can with a stick and his hand alternately and was a very able singer. The compound was spotlessly clean and all the family very welcoming. One lady, a widow said she had taken it upon herself to "look after" the disabled in her community... she spoke English and was very helpful and caring.

Malisa was selected at random for monitoring, she was 16 years old normal birth but had become sick at 4 years old become hemi-plegic ?Polio. Had attended school up to P5., but too weak to carry water or pound cassava, two major contributions to the household for a young girl. She also liked drumming and was quite an actress according to her mentor. Discussed keeping chickens, trade training. No communication disability.

Also discussed help for small boy with polio and contractures.

Child with rubber band constrictions round ankles from German measles? deformed toes and fingers. 10 year old boy who had polio, makes ropes, now walking with a stick. no communication problems.

Went to third venue but group had already left, Message had been confused and they had come in the morning.

## 2.2.95

Visits were made with John Oyango in Kilewa sub-county. He reported having problems with the forms he had filled them in for 3-9 year olds having arrived late at the training session and missed that part of the news. He had registered 120 cases altogether 10 with communication disorders he had used the forms only for people with communication disorders, advice and instruction was given re this issue, He had only filled in 3 forms one of these was chosen for monitoring.

Jesca Nyachwo reported anoxia at birth, took a long time to breathe, Multiply handicapped. Visual impairment, difficulty with feeding, cannot walk or sit, Cerebral Palsy Problems with stomach, under nourished, cries and laughs, responds to sounds. Child seemed essentially starved. Advice re- feeding and general care management.

Other cases: CP. Child 3 years not fed, mild Cerebral Palsy another baby born after, so now does not get the breast, child's father was a government official came to see us, but saw no reason to be concerned about the feeding of the child. Yet child was crying with hunger. Ate a biscuit I gave her as quickly as she could, in case it was taken from her., Showed Mother and other members of the family had to feed her, explained that it would take up quite a bit of the day to get enough food into her, the process was not quick. Micro cephalic who ate all the time!  
Advice re over feeding.

Visited Mr. Dakkar, Buteleja. We arrived to see Mr. Dakkar a little early because we wanted to get away earlier so we could return to Kampala that night. However he was not there. His wife said he had gone to visit some cases who had come early in the morning and had started to go home. There was confusion with another arrangement of CBR



workers who were visiting another centre close by... the result was that we saw 3 people who had gathered there but Mr. Dakkar only arrived back just as we were leaving, actually he chased the car on his bicycle for about one mile!! No. 2 of the 3 was picked at random for monitoring. This was a MH child with an eye complaint, sent to Dr. in Health Centre nearby for medicine for eye, advice re stimulation and expectations for Mother. Mother seemed rather negative or perhaps it was lost in translation.

Also saw Irene, hyperactive Mentally Handicapped (MH), Didn't want to wear her knickers!! Threw things including my camera! Took her photo with local teacher who was helping.

## IGANGA

The DRO and the Acting CDO met with us on 20,1,95 to discuss any problems concerning the administration of the questionnaire. The issues which had been raised by the CDAs were as follows:

1. The CDAs complained of having no money for transport, and could therefore not visit the number of cases that they would wish. They were reassured that the extra money and the bicycles would be forthcoming after the completion of their training course, and that it was not essential to the research that they visited vast numbers of cases, only that they recorded the details of the cases they were seeing. All the officers concerned felt there would be enough cases near at hand to each CDA for them to have more than enough work to do without worrying for the moment about the more remote cases which they were unable to visit.
2. Re-confirmation was given that a form should be filled in for EVERY case under the age of 18 years. The DRO felt they had all understood this but the previous day we had met one of his CDAs who had not understood and was only filling in the forms for children with communication disorders.
3. The DRO was asked to check the forms when they were handed to him, and to expect the completed forms to be returned to him before others were handed out.
4. The 4 selected CDAs were identified and the DRO was asked to draw up an itinerary for them to be visited on 15th and 16th February. These dates were later changed to the 6th and 10th of February so that the visits could be combined with the trip to Mbale and petrol could be saved on the journey.

### 6.2.95

Left Kampala in the morning after a difficult exit due, this time, to the collection of several typewriters and duplicating machines, which were to be delivered to each area. But nobody knew which store they were in. Arrived in Iganga at 2pm. Visited with Namukina Gorelli of Bulamagi s/c, had seen 20 cases, was upset with us because had been told that we would be coming in the morning. This was not her fault but the DRO who is very swarve and a slick talker but does as little as possible. We arrived at her sub-county there was only one case to greet us and she had not filled form for him. However she seemed to have understood the criteria for recording the cases and we visited on foot together a little baby with club feet, who had been selected at random from her forms for monitoring. Also one physically impaired child, Joy who was out at school but interviewed the mother.

Then went with Mr. Opio Joseph, he had filled 15 forms altogether selected to visit Silvia who was 14? weighed 10 kilos at the most! Had had malaria at 5 years old, normal till then, now suffering from severe malnutrition, Physically Handicapped (PH) Paralysed except for one hand and face muscles. although chewing and swallowing were affected. She seemed however to understand what was said to her and could sign with her one hand.



Also saw Michael, hydrocephalic. in Namungalwe s/c He could talk and understand but could not sit up or walk. Father a strange man, later told he was the local witch doctor, several disabled people in his compound, the other officers thought he 'collected them, felt he was an evil man, girl dwarf and PH man.

Called to visit another CP child but she had died on Saturday.

10.2.95.

Visited CDA Mpiiya Stephen at Magada. He reported problems with the forms. His English was very poor and so it was difficult to explain things to him quickly, no one else seemed to speak his dialect either. There seemed to be many inconsistencies had used a cut off age of 15.

Saw Suzani, this was the 2nd choice, she appeared severely autistic, did not communicate or recognize or relate to people. Well looked after by family, would not shake hands, yet can understand things sometimes, obviously hears, and when she speaks her speech is clear. However usually doesn't bother to communicate except to shake the door when she wants to go out to the toilet. Completely clean. Cries when sick, laughs when exited. Head shaved because of lice. Checked form for incorrect answers, but this was a complicated case.

Insisted on Greeting us at the chiefs house..... more food!!?

Picked up David Kateteyi who seemed to have understood how to fill in the forms. Selected and visited Isima MH child, well looked after and loved by family, cerebral malaria regularly .... fits and fever, taken to clinic for treatment regularly chloroquine and valium. Understands a little but is confused and cannot remember very long so cannot carry out instructions.

Visited Ngobi Geoffrey 17 hearing impaired, been treated in hospital by Swiss Doctor waiting for hearing aid.

